Improving Systems of Follow-Up Care for Traumatic Brain Injury

Proceedings of a Workshop

Improving Systems of Follow-Up Care for Traumatic Brain Injury

Tamara Haag, Chanel Matney, and
Katherine Bowman, *Rapporteurs*

Forum on Traumatic Brain Injury

Board on Health Sciences Policy

Health and Medicine Division

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Proceedings of a Workshop

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Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings, nor did they see the final draft before its release. The review of this proceedings was overseen by **LESLIE Z. BENET**, University of California, San Francisco. He was responsible for making certain that an independent examination of this proceedings was carried out in accordance with standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the rapporteurs and the National Academies. We also thank staff member **ALEXANDRA BEATTY** for reading and providing helpful comments on this manuscript.

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BOXES

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Acronyms and Abbreviations

ACL	Administration for Community Living
AI	artificial intelligence
AWS	Amazon Web Services
BAC	Brain Attack Coalition
BETTER	Brain Injury Education, Training, and Therapy to Enhance Recovery transitional care program
BIAA	Brain Injury Association of America
CBT	cognitive behavioral therapy
CDC	Centers for Disease Control and Prevention
CHOP	Children's Hospital of Philadelphia
CPG	clinical practice guidelines
CT	computerized tomography
DoD	Department of Defense
DRG	diagnosis-related group
ED	emergency department
EMS	emergency medical services
EHR	electronic health record
FITBIR	Federal Interagency Traumatic Brain Injury Research Informatics System

GCS	Glasgow Coma Scale
HSS	Hospital for Special Surgery
LHS	learning health care system
MCO	managed care organization
MCW	Medical College of Wisconsin
NASEM	National Academies of Sciences, Engineering, and Medicine
NASHIA	National Association of State Head Injury Administrators
NINDS	National Institute of Neurological Disorders and Stroke
OSU	Ohio State University
OT	occupational therapy
PCP	primary care provider
PM&R	physical medicine and rehabilitation
PT	physical therapy
QR	quick response (code)
RN	registered nurse
TBI	traumatic brain injury
TRACK-TBI	Transforming Research and Clinical Knowledge in Traumatic Brain Injury
UCSF	University of California, San Francisco
USC	University of Southern California
UTSW	University of Texas at Southwestern
VR	vocational rehabilitation

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Introduction[1]

Traumatic brain injury (TBI) is a condition that affects more than 5 million Americans and 60 million people worldwide each year; its prevalence is highest among the youngest and oldest members of society and in military and athlete populations. Despite this burden, TBI received little public awareness or funding in comparison with other neurological disorders until recent decades. More than 80 percent of TBIs are classified as "mild"—as determined by Glasgow Coma Scale scores of 13–15—yet these injuries can have acute and chronic effects on the injured individual's functioning and on the patient's family members and caregivers. Indeed, more than 50 percent of patients diagnosed with mild TBI have functional impairments 1 year postinjury (Nelson et al., 2019). Moreover, there continue to be critical gaps in TBI treatment. For instance, less than half of patients treated at Level 1 trauma centers for mild TBI receive any follow-up care after hospital discharge (Seabury et al., 2018). Greater awareness of TBI within the U.S. military and sporting communities in the last 10–20 years has illuminated the need for advances in TBI diagnosis and management more broadly.

Michael McCrea, a professor of neurosurgery and neurology and director of Brain Injury Research at the Medical College of Wisconsin, and chair

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[1] The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the National Academies of Sciences, Engineering, and Medicine, and they should not be construed as reflecting any group consensus.

of the planning committee, opened the workshop by highlighting needs and opportunities in TBI prevention, care, and research as well as recent engagement by the National Academies of Sciences, Engineering, and Medicine (NASEM) in drawing attention to these issues. In 2020, the Combat Casualty Care Research Program of the Department of Defense requested that NASEM convene an ad hoc committee of experts to explore strategies to advance TBI care and research and develop a road map to accelerate progress. The resulting report provided findings and recommendations for areas in which progress can be made (Bowman et al., 2022; NASEM, 2022), and McCrea outlined the eight recommendations it sets forth (see Box 1-1).

Oftentimes, a TBI is not an isolated, acute event, but rather a condition influenced by biological, psychological, and social, and ecological factors that can have long-term effects. A primary theme that emerged during the NASEM study is the frequent failure of TBI care in the United States to fully meet the needs of affected individuals, families, and communities (NASEM, 2022). The United States lacks a comprehensive framework for addressing TBI along the full continuum of care and across care settings, the report said, and effective TBI systems of care need to be able to

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BOX 1-1
Recommendations of the Committee on Accelerating Progress in Traumatic Brain Injury Research and Care

1. Create and implement an updated classification system for TBI.
2. Integrate acute and long-term person- and family-centered management of TBI. All people with TBI should have reliable and timely access to integrated, multidisciplinary, and specialized care to address physical, cognitive, and behavioral sequelae of TBI and comorbidities that influence the quality of life.
3. Reduce unwarranted variability and gaps in administrative and clinical care guidance to ensure high-quality care for TBI.
4. Enhance awareness and identification of TBI by health care providers and the public.
5. Establish and reinforce local and regional integrated care delivery systems for TBI.
6. Integrate the TBI system of care and TBI research into a learning health care system.
7. Improve the quality and expand the range of TBI studies and study designs.
8. Create and promulgate a national framework and implementation plan for improving TBI care.

SOURCES: Presented by Michael McCrea, Medical College of Wisconsin, May 9, 2023; NASEM, 2022.

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anticipate, respond, and evolve in a coordinated fashion. Building on that report and other efforts, in 2022 the National Academies established the Forum on Traumatic Brain Injury as an ongoing, mechanism for experts and stakeholders in the public and private sectors to undertake short- and long-term strategic discussions, address emerging issues for advancing TBI research and care, and explore opportunities for collective action. McCrea noted that the forum thus provides a venue to help advance the recommendations from the 2022 report as well as other areas of interest to the TBI community.

WORKSHOP OBJECTIVES

As McCrea emphasized, fulfilling the report's second recommendation—integrating acute and long-term person- and family-centered management of TBI—will require closing current gaps in the provision of reliable and timely access to integrated, multidisciplinary, and specialized care for TBI. To help explore these gaps and the strategies for addressing them, the Forum on Traumatic Brain Injury hosted a 1-day public workshop—Improving Systems of Follow-Up Care for Traumatic Brain Injury—to examine the needs, practices, and models for systems of follow-up care and symptom management for individuals affected by TBI, with a focus on applicability to milder injuries along the TBI severity spectrum and on care needs in the initial months after injury (sometimes also referred to as the "postacute" period).

The workshop, which was held virtually and in person on May 9, 2023, featured invited presentations and discussions to explore:

- patient and community priorities for TBI follow-up care;
- key elements that support effective follow-up, symptom management, and recovery after TBI;
- lessons from models of TBI follow-up care programs and from programs addressing other conditions, such as stroke; and
- the feasibility, scalability, adaptability, and sustainability of systems of follow-up care for TBI.

Civilian patients with mild TBI were a primary focus of the workshop, given that over 80 percent of diagnosed TBIs are classified as "mild" and many affected individuals receive no follow-up medical care after leaving a setting such as an emergency department. Sessions during the workshop explored how to enhance the continuity of care after TBI and explored examples of multidisciplinary care models, including lessons from the creation of a system of primary and comprehensive centers for treatment of stroke. The value of understanding and embracing the patient perspective

was emphasized by a number of speakers and participants throughout the workshop. Multiple speakers also highlighted the effects of social determinants of health on TBI treatment, outcomes, and recovery and the need to incorporate such considerations when designing TBI care systems. Other topics presented included the ability to use technology and innovation to maximize patient connectivity to care while decreasing the burden on the health care system, the importance of scaling and sustainability for follow-up care models, and the importance of building a learning health care system in TBI to support ongoing improvement. A learning health system is one able to anticipate, respond, and learn in a coordinated fashion, in which "science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity - with best practices and discovery seamlessly embedded in the delivery process, with individuals and families as active participants in all elements, and new knowledge generated as an integral by-product of the delivery experience." In such a system, "evidence informs practice and practice informs evidence" (IOM, 2007).[2]

ORGANIZATION OF THE PROCEEDINGS OF THE WORKSHOP

This proceedings summarizes the presentations and discussions from the workshop on Improving Systems of Follow-Up Care for Traumatic Brain Injury. Following Chapter 1 introducing gaps in follow-up care for TBI and the motivation for this workshop, Chapter 2 outlines the goals and activities of the forum's Action Collaborative on TBI Care and its working groups, including input from focus groups of TBI survivors who described challenges during the TBI recovery process and shared insights on improving care systems. The Action Collaborative represents a starting point among the Forum's members by which post-TBI needs are addressed, and this workshop will also inform future Action Collaborative and TBI Forum thinking on these issues. Chapter 3 explores necessary and vital components of systems of follow-up care for TBI and describes several models addressing care continuity and providing multidisciplinary post-TBI care to illustrate elements of success and lessons learned. Chapter 4 examines key considerations beyond the clinic for achieving more effective TBI care and recovery , including the importance of social determinants of health, partnerships with community organizations, and the intersection of trauma and TBI. Chapter 5 highlights several strategies and opportunities for improving systems of follow-up care for TBI, focusing on the roles

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[2] See also the National Academy of Medicine's Learning Health System Series at https://nam.edu/programs/value-science-driven-health-care/learning-health-system-series/ (accessed August 25, 2023).

of program certification, financial incentives, and information management systems. Chapter 6 summarizes a concluding discussion integrating insights from the workshop into change efforts. Appendix A contains the reference list. See Appendix B for the workshop statement of task and agenda and Appendix C for brief biographies of speakers and planning committee members.

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Action Collaborative on Traumatic Brain Injury Care

Key Messages Highlighted by Individual Speakers

- For the nearly 5 million adults in the United States who sustain a traumatic brain injury each year, follow-up care to aid their recovery is frequently not offered and often is wholly unavailable. Creating a nationwide, accessible, equitable, sustainable, and evidence-based system of postacute care is an overarching and achievable aim. (Manley, Markowitz)
- The forum's Action Collaborative on TBI Care is working to address research, education, and care gaps with an initial focus on adult individuals with community-acquired TBI. (Manley)
- Under the umbrella of the Action Collaborative, and incorporating input from patients and families, the Clinical Practice Guidelines working group is analyzing and distilling guidance for medical providers on managing the most common post-TBI symptoms. (Lee, Silverberg)
- The TBI Education and Discharge Instructions working group is modifying existing CDC materials and developing new materials to help fill identified gaps in patient education, including return-to-work information. The group is beginning to discuss the challenging matter of improving dissemination of TBI education materials, such as through integration with electronic health records. (Breiding, Harris)

- The Follow-Up Care After TBI working group is motivated by a pressing need for system-level improvements to enable follow-up care for patients with TBI, which is critical to individualized evaluation and treatment. The group has identified goals for the creation of multidisciplinary TBI follow-up care systems, to help inform care system improvements and the potential future creation of pilot demonstration sites. (Hammond, McCrea)
- The Designing a Learning Health Care System for TBI Care working group is partnering in the development of a pilot software application to guide TBI patients through symptom management and follow-up care, aiming to also collect data to improve the care system. (Barde, Jacques)
- The Patient Perspectives working group held focus groups to identify implications for TBI care. Based on these conversations, follow up care to improve recovery after mild TBI needs to call attention to the potential significance of a TBI; teach brain health and how to promote the brain's healing plasticity; encourage resilience and a mindset of improvement; provide support and make patients feel less alone; and enable the treatment of psychological trauma. (Hamilton)

NOTE: This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

The first session of the workshop featured reports from the working groups that are part of the forum's Action Collaborative on Traumatic Brain Injury (TBI) Care and described the groups' progress and next steps. Forum members recently launched this Action Collaborative to advance care for community-acquired TBI, with an initial focus on follow up care for adult TBI at the milder end of the severity spectrum, a key issue also addressed by this workshop.

INTRODUCTION TO THE ACTION COLLABORATIVE ON TBI CARE

Geoffrey Manley, professor and vice chair of neurological surgery, University of California, San Francisco (UCSF) and chief of neurosurgery, Zuckerberg San Francisco General Hospital, highlighted several current gaps in TBI research and follow-up care and introduced the goals of the

Action Collaborative. It has been reported that a majority of individuals with mild TBI receive little to no follow-up care (Seabury et al., 2018). Individuals who have the capacity to recover may experience disability instead, he said, because of the false assumption that this lack of follow-up care is related to an absence of post-TBI symptoms. In the absence of disease-modifying drugs for TBI, treatments to manage and address the various symptoms a person may experience after TBI can improve their quality of life. The research community has made substantial efforts to understand the TBI care needs of the sports and military communities, and of individuals with moderate and severe TBI, but less is known about the care needs associated with recovery following the often inaptly characterized "mild" TBI, in community-acquired settings, meaning TBI associated with accidents affecting community members. As a result, the Action Collaborative seeks to gather input on essential components for improved care systems for community-acquired TBI, with a focus on follow-up care in the first year postinjury, clinical guidance on symptom management aimed at outpatient TBI programs and primary care providers, and enhanced TBI education, discharge, and ongoing care instructions. The Action Collaborative has established several working groups to make progress in these areas, and these working groups also maintain regular communication and coordination to stay aligned in their efforts.

Manley emphasized the importance of incorporating patient and family input when addressing gaps in TBI management and care. Manley noted that as many as 50 percent of adult TBI patients with injuries at the milder end of the spectrum receive no discharge instructions, and many patients and families are not even aware of their TBI diagnosis after receiving emergency department (ED) treatment. Furthermore, the majority of practitioners in the health care community are unaware of the long-term consequences of TBI in patients who have Glasgow Coma Scale scores in the mild range of 13 to 15, approximately half of whom will not have fully recovered at 12 months postinjury (Nelson et al., 2019). Providers often tell ED patients with a mild TBI that a normal computerized tomography (CT) scan signifies that their symptoms should disappear within a few days, he said; individuals are thus undereducated and unprepared when they experience persistent symptoms. To advance efforts to better address the needs of the 5 million individuals who seek ED care for TBI each year, Manley ended with a call to develop and scale a demonstration project incorporating key elements for improved post-TBI care and education, informed by the Action Collaborative working groups and other efforts.

REFLECTIONS FROM
ACTION COLLABORATIVE WORKING GROUPS

Clinical Practice Guidelines

Katherine Lee, director of Casualty Management Policy & Programs and lead for the Department of Defense Warfighter Brain Health program, Office of the Deputy Assistant Secretary of Defense for Health Readiness Policy and Oversight, highlighted the Clinical Practice Guidelines (CPG) working group's objective of enhancing support for community-based health professionals through evidence-based clinical management recommendations for optimizing the recovery and wellness of people with TBI. The working group has drafted a scope statement to inform the creation of guidance based on such recommendations. Although this scope statement is not yet finalized, the objective of a guideline or other clinical guidance in this area is to improve postacute clinical management of two groups of adults with TBI: those who can care for themselves at discharge from acute care and those who do not require acute hospital care. The intended CPG would provide a set of priority recommendations for health professionals in primary care community settings, including guidance on referral thresholds for specialty care. This proposed CPG would not address prehospital or hospital-based care, nor would it include recommendations to medical or allied health professionals in specialty care settings. Lee emphasized that this scope would continue to evolve through working group discussions, as appropriate.

The working group has identified 17 existing TBI CPGs that have been published or updated within the last 10 years as a foundation that may be built upon. Currently, the working group is mapping the overlap of these guidelines in such areas as early patient and family education and the timing and frequency of follow-up visits. Lee noted that many current CPGs are focused on the acute management of TBI and on specific subgroups of TBI patients, such as military and sports communities and those with severe TBI. She also noted that existing CPGs tend to be impractically lengthy, spanning more than 50 recommendations. The working group seeks to build on the existing base to create a targeted CPG or other form of guidance focusing on the 10 most effective actions clinicians can take, targeted to the weeks and months following a TBI diagnosis and with a focus on priorities identified by TBI patients, their families and primary care providers (PCPs). Moving forward, the working group plans to (1) finish mapping the overlapping areas in existing CPGs and identify any areas not addressed, (2) use patient and provider input to prioritize areas to include in the anticipated new CPG, (3) identify actionable clinical recommendations, and (4) synthesize and coordinate with other Action Collaborative working groups to ensure coherence, standardization, and effect before wider dissemination.

TBI Education and Discharge Instructions

Matthew Breiding, acting deputy associate director of science in the Division of Violence Prevention, Centers for Disease Control and Prevention (CDC), reported that the TBI Education and Discharge Instructions working group is striving to improve the educational materials provided to patients after a TBI. After identifying gaps within example discharge and education materials collected by members of the Action Collaborative, the working group is currently modifying existing materials and developing new ones to fill these gaps. Materials developed by the CDC Heads Up pediatric education initiative are a primary resource in this effort.[1] These materials include discharge instructions, symptom-based recovery tips, and a school-based accommodations letter. Research indicates that the number of accommodations provided to students increases when accommodations letters such as the one created by CDC are used, added Breiding. Because the Heads Up materials focus primarily on the needs of children and youth, the working group is creating similar resources tailored to adults with TBI, including return-to-work instructions. The aim is for the materials to be further refined and ultimately made available through the CDC website. Incorporating input from the CDC National Institute of Occupational Safety and Health, the working group is developing information for two sets of materials that patients could provide to employers. The first document outlines instructions and accommodations specific to the needs of people who have experienced TBIs but who, in the interest of privacy, do not wish to disclose their TBI diagnosis to an employer; it does not explicitly mention TBI. A second document contains TBI-relevant information that employees could choose to provide to their places of work.

The next steps for the working group entail soliciting feedback on these materials from the Action Collaborative, forum members, and others, creating user-friendly and attractive designs for the content, and developing videos and materials with embedded quick response (QR) codes. The group is also considering how to address additional gaps in patient education, beyond return-to-work content. For instance, older adults—who face an increased risk of TBI associated with falls—could benefit from patient education materials that focus on reducing their fall risk and the balance-disturbing effects of some medications. The working group is also discussing methods of improving the dissemination of TBI education materials, such as integration into electronic health records (EHR). Health care provider education is another key area identified by the group and recent NASEM report (NASEM, 2022); CDC has made progress in pediatric TBI

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[1] More information about the Centers for Disease Control and Prevention Heads Up resources and tools is available at https://www.cdc.gov/headsup/index.html (accessed June 8, 2023).

education, but efforts are needed to expand provider education related to adult TBI.

Odette Harris, Paralyzed Veterans of America Professor of Spinal Cord Injury Medicine, and director of Brain Injury, Department of Neurosurgery at Stanford University School of Medicine and deputy chief of staff, Rehabilitation at the Veterans Affairs Palo Alto Health Care System, added that the working group is focused on creating standardized resources that can be continuously updated in a sustainable way. This focus served as the impetus for building on existing materials rather than creating entirely novel resources. Harris and Breiding noted an ongoing discussion about whether *mild TBI*, *TBI*, or *concussion* is the most appropriate term for care providers to use with patients. The group has not reached agreement as to which term is most effective, accurate, and optimally lends itself to dissemination. To inform its work, the working group aims to enlist patients to test draft materials and provide feedback on terminology preferences and on the helpfulness and relatability of the resources.

Follow-Up Care After TBI

Flora Hammond, professor and chair of Physical Medicine and Rehabilitation at Indiana University School of Medicine and the chief of medical affairs and brain injury co-medical director at the Rehabilitation Hospital of Indiana, reiterated the observation that despite many individuals experiencing symptoms for months or years post-TBI, fewer than half of all patients receive any form of follow-up care (Seabury et al., 2018). The Follow-Up Care After TBI working group is striving to identify core elements of a best-practice model for postacute clinical TBI care. The group's discussions have included optimizing patient care flow by identifying points of entry into the follow-up care system and identifying mechanisms to connect patients to needed care. For instance, patients could be directed to an online portal that would guide their care along established pathways and measure their outcomes. Additionally, in a best-practice TBI model, multidisciplinary care is needed to facilitate patient progress, establish access, and provide specialized care when needed. Such a model entails considering patient volume and referral processes, as well as practices and strategies for operational resourcing and establishing return on investment. Furthermore, the creation of a learning health system for TBI would enable the collection of data records to build the evidence base aimed at improvements in care and care practices, thus facilitating the identification of steps that lead to best outcomes for patients. Hammond highlighted the guiding challenge of designing care solutions that are both individualized and scalable.

The working group has identified eight multidimensional goals for a TBI follow-up care system (see Figure 2-1). *Connectivity* involves ensur-

CONNECTIVITY	TOUCH POINT	TRACK RECOVERY	EXPECTATIONS
Ensuring linkage of patient from ED/hospital discharge to follow-up care path	"Our TBI Care Team is here for you and will be with you on your recovery journey"	Monitoring early recovery, need for follow-up, resuming normal activities	Framing common symptoms, prognosis, follow-up care, return to activity

EDUCATION	CHARACTERIZE	SCALEABLE CARE	HOME-BASE
Provide helpful tips to promote recovery, recommended practice for return to activity	Determine patient's predominant symptom profile to guide individualized care	Tiered levels of follow-up care (virtual, in-person, multi-disciplinary) based on patient need	Longer-range connection "We are here for you as you continue on your recovery journey"

CHALLENGE: Building scalable solutions for individualized patient care

FIGURE 2-1 Multidimensional goals of TBI follow-up care.
SOURCE: Presented by Flora Hammond, Indiana University School of Medicine, May 9, 2023; Michael McCrea, Medical College of Wisconsin.

ing that medical personnel link patients with the defined path of care before discharge. A *touch point* conveys to patients that they will have ongoing support throughout their recovery process. *Recovery tracking* monitors symptoms and determines when individuals require additional care. *Expectation setting* includes framing common symptoms and providing information on prognosis and follow-up care. *Education* involves providing tips to promote recovery and recommended practices when returning to activities. *Characterizing* a patient's predominant symptom profile guides individualized care. *Scalable care* includes tiered levels of follow-up care that could be accessed according to patient need. *Home base* provides a mechanism for longer-term connection throughout a patient's recovery process.

Designing a Learning Health Care System for TBI Care

Adam Barde, senior principal, and Glen Jacques, managing director, at Slalom Consulting, described a learning health care system (LHS) app their company is developing in conjunction with members of the LHS working group and Amazon Web Services (AWS) to meet the goal of reimagining well-connected postacute TBI care that continuously captures data to improve systems of care. To obtain TBI patient input in the design process, the group interviewed TBI survivors. Jacques noted that patients routinely commented about the lack of education they received but often recounted feeling confused and overwhelmed at hospital discharge, indicating that discharge may be an inopportune time for medical providers to offer detailed education and follow-up instructions. As Barde and Jacques noted, one TBI survivor who participated in focus group discussions commented,

> I was struggling with communicating and focusing for more than a few seconds, and they sent me home with a 20-page packet. The whole [discharge] process was overwhelming; it was not easy to understand in a concussed state.

Although TBI patients are stable at the point of discharge, their recovery journey is only beginning, said Jacques. To create a recovery process that helps patients return to baseline more effectively, the working group partnered with Slalom Consulting and AWS to use a "design thinking" process to better understand TBI patient needs and how to meet them. This design thinking process guided the group through the steps of discerning the challenges to address, defining users and stakeholders, interviewing patients to develop a deep understanding and empathy, and generating innovative solutions. The process produced a patient journey map that describes the desired experience, and in turn enabled specification of technical require-

ments and initial design for a pilot digital app that patients could use throughout their recovery.

Barde demonstrated the experience of using the pilot approach and app under development. At discharge, he said, TBI patients would be given a simple document directing them to the app's website or would be assisted by medical personnel to add it to a mobile device. During onboarding, patients (or their proxy) would create an account using a one-time text for identity verification in lieu of creating a password, thus relieving the patient of the need to remember a password during her state of recovery. Next, the app would provide a description of what to expect during the first few days postdischarge. Upon onboarding, patients would be immediately able to access educational content and resources—including short videos and guided meditations—curated to their unique circumstances. On days 4, 9, 14, and 28 after the injury, the app would prompt patients track and report their symptoms through a user interface designed to simplify the input process. The patients would see their symptoms and severity graphed over time. Based on their responses, the app may advise a patient to seek immediate care at an ED or follow-up care from a PCP or specialist to address post-TBI sequelae, ideally enabling a quicker return to baseline functioning and wellness.

The working group envisions the pilot app and other tools as part of a learning health care system that continuously improves the patient experience by using data analytics and ongoing learning, said Barde. Various levels of EHR integration will be key for clinician workflow, he added. In its prototype form, the app enables patient engagement and system tracking. In the future, the app could also be designed to automatically collect patient data directly from wearable devices. Researchers may be able to access such datasets to gain a deeper understanding of patients, improve care practices, and foster population health, Barde concluded.

Patient Perspectives

Scott Hamilton, an entrepreneur and TBI survivor, reported on the qualitative research he and colleagues conducted under the Patient Perspectives working group, focused on learning by listening. Four TBI consumer focus groups of eight participants each were held in Pittsburgh and Milwaukee.[2] All participants had been diagnosed with TBI within the year prior and most were diagnosed with TBI on the milder end of the spectrum, although some

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[2] A white paper authored by Scott W. Hamilton and Alan Hamilton describing the focus group process and presenting themes that emerged, is available at https://www.nationalacademies.org/event/05-09-2023/improving-systems-of-follow-up-care-for-traumatic-brain-injury-a-workshop (accessed July 26, 2023).

had experienced multiple TBIs. A number of themes emerged across these four focus groups. For example, many patients expressed that medical professionals who made their TBI diagnosis tended to downplay or minimize the consequences of the injury and, in some cases, did not explicitly state the TBI diagnosis. As reported by Hamilton, a 37-year-old woman said,

> I wasn't even told I had a concussion. I found out by looking at my paperwork from the ED visit. And then they didn't give me any advice on what to do. I just started looking it up on the internet. I never had follow-up on anything.

Stigma was frequently cited by participants, many of whom did not feel comfortable discussing their TBI with others. One focus group member said, "I'm not gonna go advertising to everybody that I've had a brain injury." Another remarked, "It's frustrating, but I don't want anyone to realize what I'm going through. I try to hide it as much as I possibly can. It's a stigma." Hamilton emphasized that stigma was even felt with medical professionals, as participants described feeling that their ongoing symptoms were minimized and not taken seriously. This sense of stigma can lead to isolation when TBI survivors feel they cannot talk to others about their experiences, he said. Many focus group participants reported feeling alone, regardless of whether they lived on their own or with family. They indicated a need for practical and psychological support and advocacy, remarking about craving a caring, sympathetic person who understood their needs. This sense of isolation appeared to be heightened by the burden they felt their needs placed on others.

Furthermore, focus group participants did not understand the plasticity of the brain and how to facilitate their healing, said Hamilton. People expressed accepting the "new normal" of their limitations, not recognizing that neuroplasticity may generate improved functioning. He cited his own TBI trajectory as an example of recovery, albeit one that lasted a decade. Returning to preinjury functioning is possible, he said, but it may require treatment and patience. Many participants indicated an eagerness for self-help activities, but lacked information on steps they could take to hasten healing. One 48-year-old man remarked,

> Tell us more stuff that you can do for self-care. I hate Brussels sprouts, but if someone said that eating Brussels sprouts would make my brain back to the way it used to be, I'm like, oh boy!

Hamilton noted a tendency within the medical community to hold off on making recommendations until multiple randomized controlled trials indicate an intervention is effective. However, patient focus group partici-

pants indicated frustration, helplessness, and powerlessness in the absence of steps they could take to improve their health. If a measure shows indications that it could improve TBI outcomes and is not associated with clear negative effects, he suggested that it should not be withheld from TBI patients pending establishment of a more definitive evidence base.

Many participants also described experiencing psychological trauma during their injuries that had not been sufficiently addressed, Hamilton added. In addition to the trauma to their brains, some group members referred to the experience of living with long-term, untreated symptoms as traumatic. A 24-year-old male participant commented,

> This is all traumatic because we're dealing with this stuff to this day. Short term … we were throwing up and having nausea. The long term is right now: memory issues, remembering things, mumbling, ringing in the ears.

Another remarked, "I feel like all of us, all eight of us, have trauma from this." A range of treatment options is available to help address symptoms from brain trauma, but most of the participants had not been referred for such interventions. Hamilton emphasized that among the 32 total participants, the best reports of postacute care and education came from participants who had been recruited into a study conducted by the University of Pittsburgh Medical Center. A 60-year-old male reflected:

> The treatment was spot on. They didn't rush me, and they said, "This is what you're gonna see. This is what you're gonna feel. You can't drive for a month. You can't work for a month. Here's who you follow up with, and this is when we want you to follow up." You know, they called me to make sure I was gonna make the appointments.

Hamilton contended that all TBI patients should be able to receive this level of care and education.

Implications for Postacute TBI Care

Five components emerged from patient focus group feedback that should be considered in the creation of a TBI postacute care model, said Hamilton. First, the care model should encourage attention to the person's TBI through possible actions such as increasing the use of objective measures, including biomarkers to confirm diagnosis; requiring doctors to explicitly inform patients of their TBI diagnosis; and shifting terminology from *concussion* to *traumatic brain injury* to adequately convey the serious nature of the injury. Second, medical professionals should describe brain health and plasticity to patients in layman's terms. Given that between

5 and 6 million people experience TBI annually, this education could generate ripple effects and increase the odds that a person who experiences a TBI will receive sound advice about seeking medical care. Third, medical professionals should support patient resilience and empower patients by teaching them steps they can take to promote healing. Research indicates that people having higher resilience (based on measures of this characteristic) have an improved recovery prognosis (Merritt et al., 2015). Patient focus group members reported benefiting from hearing the stories of how other people were contending with and addressing similar challenges, which contributed to their resilience. Fourth, medical professionals should link patients with support and advocacy communities to reduce feelings of isolation. Fifth, the medical community should encourage screening for treatment of psychological trauma after injury. Referring to a popular weight loss app that uses a psychological approach, Hamilton noted that focus group participants expressed a desire for similar tools that could support their personal post-TBI care and recovery needs.

DISCUSSION

Amy Markowitz, program manager for the Traumatic Brain Injury Endpoints Development Initiative at San Francisco General Hospital, served as moderator and began the discussion by posing an opening question on dissemination and implementation of the proposed clinical guidance for post-TBI management described by members of the Action Collaborative. Subsequent topics arose in response to comments and questions from participants.

Clinical Practice Guideline Implementation

The first topic addressed was on strategies to expedite dissemination and implementation of clinical guidance for post-TBI management, while attending to the varied settings in which patients may access care, including the ED, PCP offices, and community practice settings. Lee highlighted policy as one of the most influential mechanisms for changing care standards within the military, although she noted that policy directives operate differently within the civilian sector. Policy compliance can be evaluated using established metrics, she said. Didactic, multidisciplinary training events are also a vehicle for educating practitioners on the use of effective tools. Additionally, using word-of-mouth to generate awareness around the ease and effectiveness of implementing guidance on TBI management could create culture shifts that hasten adoption of new guidelines. David Okonkwo, Professor and Director, Neurotrauma Clinical Trials Center, University of Pittsburgh School of Medicine, remarked that the equivalent

of military policy in the civilian sector is payment and insurance coverage. Establishing appropriate reimbursement for the implementation of a guideline that affects clinical care facilitates the speed of adoption, he said. Harris added that linking a CPG to accreditation can be an effective strategy that simultaneously ties it to the motivation of payment.

Pediatric TBI Population

Flaura Winston, professor of pediatrics, University of Pennsylvania and scientific director of the Center for Injury Research and Prevention, Children's Hospital of Philadelphia (CHOP), noted the absence of children in the Action Collaborative working group reports. Markowitz replied that adult care is the chosen starting point for this particular set of efforts, and that levels of TBI follow-up care may sometimes be lower for adults than for children. Manley highlighted the work CDC has contributed to the awareness of pediatric TBI via the Heads Up education initiative previously mentioned. The Action Collaborative may incorporate a focus on children after addressing the current gap in adult TBI care, he said. Christina Master, professor of clinical pediatrics, University of Pennsylvania and Co-Director, Minds Matter Concussion Program, CHOP, added that parallel pediatric work is in development through her organization and others, and these efforts can synergize with the Action Collaborative work focused on adults. In the future, Manley said that the Action Collaborative also plans to consider the specific needs of adults over age 65, who constitute an important part and the fastest growing proportion of the population that sustains a TBI.

Data Gaps in Understanding Which Patients Will Need Follow-Up Care and Potential Effects on Capacity

Ramon Diaz-Arrastia, John McCrea Dickson, MD Professor of Neurology and director, Clinical TBI Research Center at the University of Pennsylvania, noted that the vast majority of the 5 to 6 million people who suffer a mild TBI annually will recover, and he remarked on the potential risk of overmedicalizing the condition. He added that the participants in the study he coauthored, which found that half of the patients who visited the ED for mild TBI had not recovered within 12 months, were patients at a Level 1 trauma center who consented to participate in a study and follow-up visits (Nelson et al., 2019); it is possible results could differ for other TBI patient populations. Prognostic tools are needed to differentiate between the 15–20 percent of mild TBI patients who will experience long-term symptoms and the 80–85 percent who recover completely, he emphasized. Hamilton responded that although the participants in the

patient focus groups he conducted were not randomly selected, he observed the reverse, with approximately 20–25 percent of TBI survivors experiencing full recovery with the remainder struggling with ongoing issues that were not treated in the weeks and months postinjury.

A participant described that his 28-year-old daughter experienced a head injury at the age of 5, and he was never told that she had a TBI. Although she would qualify as having a mild TBI, he reported that nothing about the injury's effects on her life had been mild. She, like many others, received no follow-up care, and therefore she is not in any system that could be used to collect TBI data, he said. Given that so many people with TBI receive no or limited medical care, limited data is collected on the majority of TBI survivors, and accurate conclusions about the percentage of patients who recover fully cannot be well determined, he maintained. Manley reiterated that additional data are needed to fully understand the scope of the issue, and this gap warrants further investigation. Diaz-Arrastia acknowledged the need for better data and contended that this data gap does not eliminate the risk of overmedicalizing the condition, noting that factors identified as prognostic for poor recovery after mild TBI include pre-existing psychological and personality factors. Michael McCrea, Medical College of Wisconsin, underscored the need for a neuro-bio-psycho-socio-ecological model of TBI (Nelson et al., 2018; NASEM, 2022) that considers not only the injury itself but also the person experiencing the injury and the patient's response to injury.

Frederick Korley, professor and associate chair for research, Department of Emergency Medicine, University of Michigan, commented that overmedicalizing mild TBI could lead to overburdening care clinics with patients who do not require this level of follow-up care, pointing again to the need for improved prognostic tools to prioritize those patients who are likely to experience longer-term symptoms. McCrea referred to the second recommendation in the NASEM TBI consensus study report, which states "All people with TBI should have reliable and timely access to integrated, multidisciplinary, and specialized care" (NASEM, 2022). He emphasized that this statement does not equate to a recommendation that all individuals who experience mild TBI should be seen in a multispecialty clinic within a week of injury, but that those who experience ongoing symptoms should have a pathway to receive follow-up care. Current TBI specialty care models do not cover many parts of the United States, he said, thus a new model for improving follow-up care needs to be scalable in different care settings. Hammond added that funding, institutional involvement, and community engagement will also be needed to create pathways to care for individuals lacking insurance.

Patient Considerations in Resource Development

Noting the range of symptoms that can occur after TBI, Katherine Bowman, director of the Forum on Traumatic Brain Injury, National Academies of Sciences, Engineering, and Medicine, asked how these symptoms can be considered in the process of creating the educational materials, resources, and apps described by the working groups. Hammond replied that materials will need to be designed with simplicity and understandability in mind so patients and their family members have access to needed information without feeling overwhelmed by these resources. Michael McCrea added that the working group's goal is not to treat 5 million individuals each year in specialty clinics; rather, the goal is to provide people with resources to inform decisions about whether further postacute care is warranted.

Hamilton commented that discharge is not an opportune time to convey detailed information to someone who has just experienced a TBI. Additionally, the patient focus group members with whom he spoke conveyed a dislike for generic materials. Personalized resources that include a patient's name and are tailored to their type of injury are more likely to be used, he contended. Health care professionals can harness technology to help create such materials. Hamilton noted a recent study that indicated that written responses generated using ChatGPT, an artificial intelligence natural language processing tool, were as accurate and conveyed a more sympathetic tone than responses written by doctors (Ayers et al., 2023). Barde remarked that another important future focus of app development will be streamlining integration with other platforms to remove data silos that require patients to use multiple apps for their various health conditions and providers.

Engaging Relevant Medical Associations

Donald Berwick, president emeritus and senior fellow, Institute for Healthcare Improvement, asked about the extent to which Action Collaborative members exploring post-TBI care issues have connected with primary care professional associations to establish an outlet for the guidelines, patient education, and discharge instructions they aim to develop. Breiding replied that for the pediatric TBI population, CDC and others have developed connections with youth organizations, sports organizations, and pediatric medical societies. Expanding the footprint for adult TBI education will require additional efforts. McCrea noted that the TBI forum is a convening arena that can help establish such needed connections, given the presence of representatives from a variety of medical associations. That said, further engagement with primary care and

family medicine communities would be beneficial. TBI treatment involves a range of medical professionals and specialties, and wide representation in the forum can improve collective problem solving and strengthen dissemination capacity.

3

Elements of a System of
Follow-Up Care for Mild TBI

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Key Messages Highlighted by Individual Speakers

- Transitional care is designed to ensure continuity of care and prevent poor outcomes during care transitions; key components include engagement, education, well-being, complexity management, care continuity, and accountability. (Hirschman)
- Care plans after TBI need to address challenges that patients and families can face in managing symptoms and recovery, including social determinants of health that affect care transitions that can lead to disparities in TBI outcomes linked to race, ethnicity, sex, and age. (Oyesanya)
- Multidisciplinary TBI clinic models can provide team-based care and services such as care coordination to effectively treat nuanced and heterogenous TBI symptoms. Challenges that patients face in accessing comprehensive TBI care include limited multidisciplinary clinic capacity and competition for resources. (Barshikar, McCrea, Shetty)
- Creating adaptive, multidimensional systems of care for TBI will be critical to ensuring proper follow-up evaluation, treatment, and education aimed at maximizing recovery and reducing disability caused by TBI. (McCrea)

NOTE: This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

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The second session of the workshop discussed the core components of transitional and multidisciplinary follow-up care for TBI patients, particularly at the milder end of the severity spectrum, as well as barriers to the implementation of these elements in care systems. Speakers shared overviews of several models and programs for transitional care and for TBI follow-up services, to illustrate these ideas and help to identify common features and differences.

KEY COMPONENTS OF TRANSITIONAL CARE

Karen Hirschman, research professor, University of Pennsylvania School of Nursing, described the role of transitional care, which is a set of time-limited, evidence-based services designed to ensure continuity of care and prevent poor outcomes during care transitions, such as emergency department (ED) visits or hospital readmissions, explained Hirschman. She provided a foundation for the conversation by first describing common issues encountered during patient transitions between care settings, organizations, and/or providers (Hirschman and Hodgson, 2018). Poor continuity of care can occur when information is not transferred or adequately communicated between different providers or between providers and patients, she said. For example, hospitals sometimes provide patients and caregivers with complex treatment regimens at discharge without allowing sufficient time for them to process the information and ask questions. Maintaining continuity of care is less likely when a patient is discharged from the hospital without understanding appropriate next steps; this can be exacerbated by health literacy issues and language barriers. Similarly, she noted that lack of collaboration can undermine the continuity of care if providers fail to engage patients and caregivers in care plans or make treatment decisions without sufficiently assessing or including patient preferences and goals. Care transitions can also be complicated by comorbid health issues (such as chronic conditions, cognitive deficits, depression, or substance abuse) and social factors, such as inadequate housing and food insecurity.

Transitional care aims to minimize the occurrence of these issues, and its core components include engagement, education, well-being, complexity management, care continuity, and accountability. Engaging patients and caregivers involves identifying their priorities, goals, preferences, perspectives, needs, and capabilities. Furthermore, professionals need to foster shared decision making, promote shared accountability, and ensure trusting, reciprocal, and respectful relationships (Naylor et al., 2013).

Hirschman noted that effective education efforts begin with providers assessing what patients and caregivers already know, determining what they need to understand, and educating them to address relevant knowl-

edge gaps. Although transitional care is time limited, it generally features multiple interventions along a continuum of support toward independence. The process of assessing well-being in patients and family caregivers needs to acknowledge their current stressors, she said—for instance, the uncertainty of not knowing what to expect in the TBI healing process—and foster person-centered coping skills with a focus on quality of life. Managing complexity involves examining and, as appropriate, streamlining medication and care plans, and identifying any underlying causes for hospitalization. This component of transitional care is particularly relevant for older patients, Hirschman said, as they are more likely to have multiple chronic conditions.

Care continuity avoids breakdowns of care and can be accomplished by providing support to patients in navigating various health and community settings. Accountability is maintained when (1) clinicians are accountable to patients and family members, (2) the care team is responsible to one another in providing excellent interventions, and (3) the organizational structure supports the team and clinicians in successful implementation of transitional care.

A model for transitional care considers contextual factors, services, and needs, said Hirschman (Grembowski et al., 2014) (see Figure 3-1). For example, a needs assessment can be used to identify a patient's social supports and caregivers; unmet needs identified through this process can be linked to additional health care and community services and resources. Ideally, transitional care improves the patient and family caregiver experience, health, and well-being while decreasing ED visits, hospitalizations, costs, and caregiver burden. Hirschman illustrated these points by describing a transitional care model from the University of Pennsylvania School of Nursing. During hospitalization, hospital staff identify patients requiring transitional care. The nurse serving as team lead engages with each identified patient and their family, conducts a comprehensive assessment, and initiates collaboration with the health care team. Within 24 hours of discharge, the team lead visits the patient at home or in the subsequent health facility to foster engagement, reassess needs, and identify goals. Interventions may involve additional home visits and are focused on collaborating, communicating, fostering coordination, promoting continuity with providers, managing symptoms, and educating patients and families to promote self-sufficiency. Hirschman noted that transitional care plans can be tailored to specific populations to prioritize beneficial interventions and provide holistic care while avoiding overburdening the medical system.
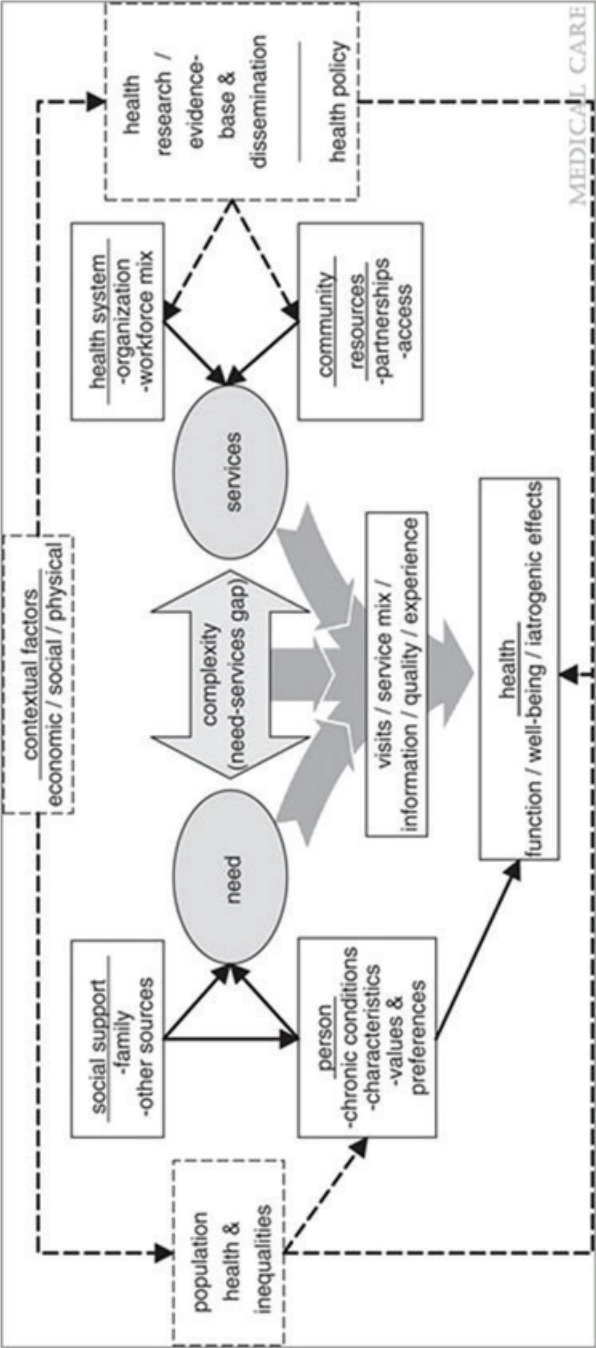
FIGURE 3-1 Conceptualization of the transitional care model. Using a transitional care model helps to provide better experience with care, improved health and well-being, decreased caregiver burden, and reduced costs.
SOURCES: Grembowski et al., 2014; Adapted version presented by Karen Hirschman, University of Pennsylvania, May 9, 2023.

ELEMENTS FOR DISCHARGE PLANNING
AND TRANSITIONAL CARE

Tolu Oyesanya, associate professor, Duke University School of Nursing, emphasized that over 6 million U.S. residents are living with TBI-related disabilities and contend with physical, cognitive, communication, behavioral, and/or emotional impairments. These challenges—which vary by individual according to factors including severity of the injury, time since injury, and age—can have substantial effects on TBI survivors and their families. As previously noted, less than half of people who sustain a mild TBI receive care; many of those who do seek treatment visit the ED and are discharged without hospital admission. Thus, the majority of mild TBI management occurs outside of the hospital via community-based primary and specialty care providers (Holm et al., 2005; Silverberg et al., 2020). The follow-up care a person may receive varies and is complicated by care continuity gaps and a limited number of providers with TBI expertise. She asserted that many providers treating patients with TBI do not have expertise in caring for this patient population.

Upon discharge, Oyesanya said, TBI patients and their families face a number of potential issues in self- and family management of injury-induced impairments (Oyesanya et al., 2021a,b). Safety issues can arise when patients do not adhere to post-TBI activity restrictions or when they engage in unsafe behaviors attributable to TBI-caused impairments affecting judgment, decision making, and impulsivity. Medication management is often challenging for TBI patients and their families, who may have difficulty remembering to fill, pick up, or take medications appropriately. Impairments can make it difficult for patients to develop strategies for these activities in both the short and long term. Challenges in goal setting or adherence to plans are common for TBI survivors and can affect one's ability to return to preinjury levels of activity at work, school, leisure, and exercise. Survivors may also face issues managing emotions, comorbidities, and disabilities. Some TBI patients experience depression, anxiety, frustration, and mood swings.

TBI can complicate the management of other conditions (e.g., diabetes, sleep apnea) and can exacerbate disorders such as attention-deficit/hyperactivity disorder and dyslexia. When patients have limited support in coping with TBI-related impairments, their quality of life can decrease and they may have substantial problems navigating their health and health care, including following up with providers of primary and specialty care as directed, adhering to care providers' instructions, communicating with providers and retaining the information they offer, coordinating care, and accessing health care services and community-based resources post discharge. She noted that TBI patients have expressed an overall desire

for more support from interdisciplinary providers during their recovery process.

Social determinants of health can affect health care transitions and influence well-documented disparities in TBI outcomes linked to race, ethnicity, sex, and age, Oyesanya noted. Care plans need to consider factors related to social determinants of health, she said—defined as "the conditions and the environment where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risks"—including economics, education, health care, housing, and social supports (HHS, 2020). As described by Oyesanya, economic stability includes personal finances, health insurance status, housing, and food security, and it can influence an individual's ability to adhere to care recommendations. Education access and quality can affect a patient's health literacy, meaning the degree to which they can find and understand health-related information and apply this to decisions about their care. Health care access and quality involves the proximity of high-quality providers, health system resources, and any language barriers that might affect a patient's ability to communicate with providers. Neighborhoods and built environments can promote or challenge an individual's health and safety, while social and community contexts determine access to community-based resources and support from family and friends.

Transitional care models can address many TBI-related challenges by ensuring coordination and continuity of care as patients transfer between settings and levels of care, said Oyesanya (see Box 3-1). Oyesanya noted that in contrast to other conditions, such as stroke and heart failure, few TBI-specific transitional care programs have been established, perhaps owing to the lack of TBI-specific transitional care standards in the United States. She is currently involved in developing one such program, the Brain Injury Education, Training, and Therapy to Enhance Recovery (BETTER) TBI transitional care program for patients discharged directly from acute hospital care to home without inpatient rehabilitation (Oyesanya et al., 2022).

EXAMPLES OF FOLLOW-UP CARE MODELS AFTER MILD TBI

Hospital for Special Surgery Concussion Clinic Model

Teena Shetty, neurologist and director of the Concussion Program in Neurology, Hospital for Special Surgery (HSS), New York, outlined evidence indicating that patients who suffer significant symptoms from TBI benefit from care provided by multidisciplinary clinics. This comprehensive care requires teamwork, which has been shown to improve effectiveness in

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BOX 3-1
Components of Transitional Care for TBI

1. Identifying family or other caregiver(s) to support the patient.
2. Planning and preparing for discharge, including written, verbal, and physical preparations for the return home.
3. Assessing patient and family needs across domains.
4. Assessing and setting goals, then supporting goal achievement.
5. Providing referrals to community-based services and resources based on needs and goals, including TBI-specific services and resources if available.
6. Delivering patient/family education and training on self- and family management of TBI and on Brain Injury Coping Skills, an educational program rooted in self-efficacy that is designed to help patients learn to cope and take charge of their postinjury care.
7. Managing medication and treatment complexity.
8. Supporting care coordination and patient navigation, particularly in the form of a primary contact to whom the patient can direct questions and support requests.
9. Ensuring interdisciplinary provider collaboration and accountability to holistically address patient needs.
10. Developing individualized urgent/emergent care plan(s).
11. Addressing patient and caregiver well-being.
12. Establishing a patient connection to a resource/service-providing entity (e.g., the Brain Injury Association of America or a state-affiliated Brain Injury Association) for ongoing support once transitional care services conclude.

SOURCE: Presented by Tolu Oyesanya, Duke University, May 9, 2023.

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the health care field across disciplines (Schmutz et al., 2019). Team-based care models improve patient outcomes and are associated with safer and higher-quality care (Jesmin et al., 2012; Rosen et al., 2018). Advantages of such models include quick verbal communication and situational awareness that streamline and improve care (Lim et al., 2021). Given the nuanced, heterogeneous, and individualized symptoms after concussion/mild TBI, high-quality care requires expertise and coordination among multiple providers (Kontos et al., 2019). The prevalence of both sports- and non-sports-related concussions calls for services for both populations that include education and management plans to effectively treat symptoms (Chang et al., 2011; Kutcher and Giza, 2014). The HSS multidisciplinary clinic model centralizes services, thereby maximizing efficiency of workflow and improving care coordination for patients, she reported.

Shetty founded the HSS Concussion Program in 2015 to define a new standard of care and influence the way that providers diagnose, treat, and

understand concussion.[1] It is an active recovery program that strives for short latency after ED discharge or referral from an athletic trainer, sport coach, school, or other source. In this way, she said, HSS functions similarly to an urgent care model despite being a tertiary care outpatient setting. The model of care uses the latest research to inform diagnosis and early interventions. Developing individualized concussion management plans, the team considers baseline level of function and targets each patient's goals. The program simultaneously offers patients access to experts with years of specialized training in concussion care. Moreover, the HSS Concussion Program model features a patient navigation component that allows providers to address the increasing complexity of TBI care. The program's goal is to improve the patient's experience by enhancing the coordination of visits, eliminating barriers to care, and offering timely service delivery. Weekly comprehensive team meetings serve as a mechanism for presenting patient cases and aligning multidisciplinary providers on cohesive, integrated care plans developed via roundtable contributions from all team members.

Concussion Care Team Roles

Shetty reported that the team features a neurologist, multiple physical therapists, sports performance trainers, a neuropsychologist, and a clinic coordinator/social worker. As a neurologist, Shetty serves as the point person of the HSS care team by developing targeted treatment plans, guiding modifications of vestibular and athletic training progressions for each patient, directing weekly care meetings, and helping the team determine decisions regarding the return to work, school, and play. Additionally, the neurologist performs comprehensive neurological evaluations to triage each patient to appropriate multidisciplinary providers and expedite care. The advanced practice provider is a physician assistant, nurse practitioner, or registered nurse who (1) oversees return-to-work/return-to-play paperwork; (2) updates clinical notes with outside consults, imaging, and medical documentation; (3) fields patient phone calls; and (4) triages incoming communications. Shetty reported that having an advanced practice provider on the team increases patient flow, assists the program in its goal of offering timely appointments, improves patient satisfaction, and likely improves multidisciplinary clinic provider satisfaction as well.

The clinic coordinator establishes relationships with patients and assists them with scheduling appointments, relaying their questions to the appropriate care team member, reviewing next steps, making referrals to other providers, and providing letters for schools and workplaces. Shetty noted

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[1] More information about the Concussion Program at Hospital for Special Surgery is available at https://www.hss.edu/neurology-concussion-program.asp (accessed June 22, 2023).

that a nonrevenue earning physician fills this role, and budgeting for a physician who does not perform procedures or exams can be challenging. However, HSS staffs this position because of the clinic coordinator's ability to increase patient compliance with the treatment plan. Because confusion is often present in the early stages of TBI recovery, the clinic coordinator ensures that patients understand all steps in their treatment plans. A research coordinator works with the neurologist to identify potential candidates for ongoing research, assists in educational outreach, and ensures patient compliance with the research protocol window. Arguably an optional part of the program, Shetty contended that the coordinator position is critical for scientific advancement in concussion treatment and diagnosis.

Given that visual abnormalities can occur in concussion and necessitate visual rehabilitation, the HSS Concussion Program works closely with a neuro-ophthalmologist, noted Shetty. A neuropsychologist evaluates whether the TBI has caused any cognitive deficits. In cases where deficits in attention, processing, working memory, or other areas of cognition are identified, the neuropsychologist uses cognitive metrics to guide the recovery process and determines when the patient's functioning has returned to baseline. Vestibular dysfunction is common in concussion, and a vestibular therapist works with patients to address dizziness, fogginess, nausea, and environmental sensitivity.

A physical therapist specializing in concussion provides neck physical therapy (PT) to patients experiencing whiplash symptoms or cervical pain or stiffness. Neck strengthening exercises have been found to improve concussion recovery and may even help to prevent TBI (Streifer et al., 2019). An athletic trainer identifies symptoms that are triggered by exercise and develops active exercise protocols individualized to patient goals, whether competitive or noncompetitive. Throughout a gradual progression of increasing exercise intensity, the athletic trainer assesses the patient, monitors patient heart rate, and provides feedback to the team until the patient is asymptomatic to maximum exertion. Return-to-play decisions rely on this feedback, and aerobic exercise can accelerate recovery and reduce prolonged symptoms, said Shetty.

The HSS Concussion Care Team does not currently include cognitive behavioral therapy (CBT) or cognitive remediation components, but Shetty stated her hope that these will be added in the future once resources can be allocated to provide these services. CBT may help facilitate recovery for mild TBI patients experiencing insomnia, depression, anxiety, psychosomatic symptoms, and headache (Al Sayegh et al., 2010). In addition, Shetty noted that CBT may help patients develop after-recovery plans. Cognitive remediation is a targeted psychotherapy, attention, and information processing exercise that may also improve postconcussion functioning.

Patient Outcomes

The HSS Concussion Care Team is working to improve outcome measurement, Shetty noted. Currently, each patient completes a postcare evaluation that is shared with the team during weekly meetings and translated into future action items. Patient recovery is measured in terms of progression toward patient-defined goals and by team member assessment. Team members can incorporate one another into the treatment plan via referrals, and the program guarantees PT appointments for each patient. The program features a "one-stop shopping model" in which the rehabilitation offices are downstairs from the neurology department, enabling patients to conveniently attend neurology appointments and PT/rehabilitation appointments in the same building. This proximity facilitates feedback between the departments about patient progress. The team works to prevent attrition and ensure compliance by addressing any barriers patients may be experiencing. Additionally, active recovery plans establish timelines for goals, and when dates are not met, the team works to identify potential barriers to goal achievement.

Next Steps

The HSS Concussion Program is also working to improve patient education and care supported by cognitive-based neuroscience, said Shetty. This involves educating patients about the sympathetic versus parasympathetic nervous system and the concept of graded exposure to activities patients may be avoiding because of predictions that they will cause pain. The team trains patients on breathing and mindfulness exercises, meditation, and using heart rate variability biofeedback to improve symptoms. HSS plans to use telehealth technology to expand care to parts of the country lacking access to multidisciplinary clinics. The team also intends to explore remote monitoring of wearable technology to aid in exercise rehabilitation.

University of Texas Southwest Medical Center Multidisciplinary Clinics

Surendra Barshikar, associate professor and vice chair of clinical operations, Department of Physical Medicine and Rehabilitation, University of Texas at Southwestern (UTSW) Medical Center, provided an overview of the parallel concussion care programs that UTSW operates at its university hospital and at Parkland Memorial Hospital, a county facility housing one of the busiest trauma centers in the nation. Before the establishment of these programs, concussion care was fragmented across various clinics and departments—such as neurosurgery, rehabilitation medicine, neurology, and psychology—operating independently and without coordination or

centralized referrals. A model system was in place for moderate to severe TBI, but not every TBI patient met the criteria for this care pathway. In 2015, the UTSW multidisciplinary concussion programs were created in concert with a standardized TBI referral process that allows self-referrals. Most of the concussion clinics in the area focus on sports injuries and provide brief assessments and return-to-play documentation; these clinics refer patients who require ongoing care to UTSW. Housed within the Peter O'Donnell Jr. Brain Institute,[2] the Parkland program requires in-house referrals and has substantial exclusion criteria that limit eligibility to complicated mild, moderate, or severe TBI or noncomplicated TBI that failed primary care management. The volume of clients seen at this clinic has created long wait times for appointments, he said.

The UTSW Concussion Program located in the university health system features eight brain injury-certified physiatrists; a brain injury fellow; three neuropsychologists; two rehabilitation counselors; providers of vestibular, neck, and spine PT; an occupational therapist who performs vision therapy; a speech language pathologist who provides cognitive therapies and remediation; and a social worker.[3] Although it is not a revenue-generating position, said Barshikar, the social worker adds value by providing care coordination, patient navigation, accommodation letters for school and work, and various other forms of assistance to help patients return to their preinjury activities and lifestyle. These in-house providers refer to other UTSW specialists as needed, including the headache clinic, neuro-otology, neuro-ophthalmology, and psychiatry and psychology in cases warranting in-depth counseling or medication management.

Changes in Concussion Program Model

The initial model used at the UTSW Concussion Program's inception was based on the theory that the timing of concussion care changes the outcome, with prompt care leading to better outcomes, Barshikar noted. The clinic prioritized patients whose TBIs had occurred within the previous month, scheduling their appointments with a physiatrist within 1 week of referral. These appointments focused on patient education and acute symptom management. Patients who had been injured 1–3 months prior to referral were seen by a physiatrist within 2 weeks. The team expected TBI psychosocial symptoms to be more common after 3 months postinjury. Therefore, individuals who were referred more than 3 months postinjury were scheduled for

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[2] More information about the Peter O'Donnell Jr. Brain Institute is available at https://www.utsouthwestern.edu/research/brain-injury/about/ (accessed June 22, 2023).
[3] More information about the UTSW Concussion Program is available at https://utswmed.org/locations/aston/uh-pmr-clinic-concussion-program/ (accessed June 22, 2023).

a combined visit with a physiatrist and a neuropsychologist, who performed a brief neurobehavioral assessment. Unexpectedly, a majority of patients were referred to the clinic 3 or more months postinjury, largely because of delays related to insurance issues or navigating the medical system. With only three neuropsychologists, the clinic lacked the capacity to carry out the initial service model.

Such challenges are reflected in the clinic's current operations, Barshikar noted. Presently, the hospital ED provides information about the clinic to TBI patients but makes automatic referrals to primary care providers. These providers may, in turn, refer these patients to the clinic, while some patients self-refer using the contact information they received in the ED. Patients with acute symptoms are generally seen within 2 weeks of referral, but other patients face longer wait times, and the wait time to see a neuropsychologist is long. The team holds biweekly meetings to discuss new patients, identify barriers to progress for existing patients, and generate potential solutions to improve outcomes. Formal outcome tracking is not yet standardized; currently, the team assesses whether the patient is better, worse, or the same at clinic discharge than at their first clinic appointment, and these data are kept in a registry of all patients.

Current Challenges

Wait times at the Parkland TBI clinic tend to exceed those at the university facility, with new patient appointments for mild TBI typically scheduled 6 months in advance, said Barshikar. This clinic has a smaller staff of two physiatrists, physical therapists, and a speech language pathologist. All other services must be referred out, and the clinic lacks a care coordinator. Emphasizing that delayed presentation for care is associated with poorer outcomes, he stated that the care patients receive at some so-called community concussion clinics does not meet standard of care and can delay patients receiving comprehensive treatment. For example, the UTSW program has treated patients who visited four or five small concussion clinics at the prodding of their attorneys before coming to the UTSW clinics. However, Barshikar noted that the UTSW clinics do not have capacity to fully meet the current need, particularly at the Parkland clinic, given its lack of neuropsychology services and the exclusion criteria in effect for services. As a result, patient access to quality care and education remains a substantial challenge. In addition, he noted that the COVID-19 pandemic generated a shift in demand for elective medical care that has presented additional demands on UTSW resources. Demand during the pandemic initially declined and in 2020, the volume of patients served at the UTSW TBI clinic decreased by 58 percent, down from 205 patients treated in 2019 to only 86. However, patients now contending with long-COVID—symptoms that continue or develop after the initial

COVID-19 infection—require many of the same components of care as TBI patients, presenting new capacity challenges from competition for limited care resources between these two patient populations.

Froedtert Hospital-Medical College of Wisconsin Brain Injury Program

Michael McCrea, Medical College of Wisconsin (MCW), introduced the Brain Injury Program established by the Froedtert Hospital and MCW almost 3 decades ago.[4] Reflective of national averages, TBI causes approximately 1,500 deaths annually in Wisconsin, in addition to more than 12,000 ED visits and 4,000 hospitalizations each year.[5] The statewide rate of TBI among older patients has increased, primarily because of falls. However, the number of older, active patients being treated at the Brain Injury Program caused by injuries while biking, skiing, or other physical activities has also increased over the past 20 years. Adolescents make up the majority of ED visits for TBI, many of which involve vehicle crashes and/or alcohol consumption. McCrea added that these statistics include state-reportable events and do not capture all TBIs treated in ambulatory care settings or those that go untreated.

Froedtert-MCW provides a full continuum of neurotrauma care, including a Level 1 trauma center, a neurointensive care unit, an inpatient neurology unit, and a dedicated rehabilitation hospital featuring a specified inpatient accredited TBI program, said McCrea. The health system treats over 3,000 patients with head injuries each year in ED and urgent care visits. Approximately 15 years ago, the facility created separate, dedicated clinics for sport-related mild TBI and civilian or community-acquired TBI. The majority of referrals to the civilian clinic come from the ED, trauma service, and inpatient rehabilitation. The clinic strives to see patients within 2 weeks of discharge, during the acute or subacute recovery phase. Exclusion criteria extends to patients who are 2 or more years postinjury.

Featuring an interdisciplinary care model, the clinic provides physical medicine and rehabilitation (PM&R), neurosurgery, neuropsychology, primary care, and rehabilitation services. Patients in need of services not provided in-house—such as physical, speech, psychology, and occupational therapies—receive fast-track referrals to providers with whom the clinic has established relationships. A focus on restoring function and maximizing mobility guides the clinic's practices.

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[4] More information about the Medical College of Wisconsin Brain Injury Program is available at https://www.mcw.edu/departments/neurosurgery/patient-care/adult-programs-and-specialties/brain-injury (accessed June 22, 2023).

[5] More information about TBI burden in Wisconsin is available at https://www.dhs.wisconsin.gov/wish/injury/index.htm (accessed June 20, 2023).

McCrea highlighted that patient diversity in the clinic offers medical residents and fellows valuable learning opportunities in TBI care. For instance, within the same day a resident may see a patient experiencing a remarkable recovery despite a Glasgow Coma Scale (GCS) score of 4 at admission and a patient with a GCS of 15 who is struggling and unable to return to work.[6] Such experiences demonstrate that recovery outcomes cannot be accurately predicted by GCS scores alone, he emphasized.

Remodeling Initiative

Historically, the multidisciplinary clinic has treated 14–16 patients per day, 2–3 days per week. Despite this high throughput, multiple pressures including the COVID-19 pandemic and physical relocation of the clinic led McCrea and his colleagues to question whether they could improve access and the patient-centered aspect of services. This led to efforts to remodel the program, which began with the assemblage of the Froedtert-MCW Post-Acute TBI Clinic Working Group, which contains representatives from neurosurgery, neurology, neuropsychology, PM&R, and service line administrators. The working group set goals of enhancing the best-practice system of care for postacute TBI and concussion and of achieving national recognition for a model of TBI care. Accepting patients from multiple points of entry—including ED, urgent care, physician offices, inpatient care, and self-referrals—necessitates a nuanced approach. A model that refers every ED discharge to a multidisciplinary clinic is not sustainable, McCrea noted, but data systems and automation can facilitate a high-volume triage process by identifying key metrics for efficacy. A patient's primary clinical phenotype will affect the interventions from which they are most likely to derive benefit, McCrea added. For instance, a patient experiencing persistent vestibular symptoms, but no psychological health challenges, will likely receive more benefit from physical therapy than from cognitive behavioral therapy. In contrast, a patient with normal cognitive functioning who is experiencing post-traumatic stress disorder symptoms requires CBT.

A revised TBI care model revolves around a common point of entry, said McCrea. The majority of TBI patients who are later treated at a multidisciplinary clinic are first seen in an ED. However, provision of ED discharge instructions tends to be inconsistent. To increase subsequent connectivity with TBI patients initially seen in the ED, the Froedtert-MCW program is beginning to use an automated follow-up system to inform the TBI care team and to provide individuals with tips to facilitate recovery.

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[6] The Glasgow Coma Scale (GCS) rates eye, verbal, and motor response. GCS scores from 3–8 constitute severe injuries, scores 9–12 are considered moderate, and scores 13–15 are assessed as mild.

Interactive Online Symptom Tracking Tool

Numerous departments within the Froedtert-MCW health system use the GetWell Loop app to connect to patients. McCrea noted that the TBI team's adoption of any app was contingent on its capability to link to the health system's electronic health records system. The GetWell Loop has this capability and enables symptom tracking and patient education on recovery facilitation and indicators that multidisciplinary follow-up care is warranted. On days 4, 9, 14, and 28 postinjury, the interactive tool guides patients through brief sets of questions that results in a blue alert in the event of recovery and full resolution of symptoms or a yellow alert in the event that symptoms are problematic or worsening. These alerts are sent to a TBI care team registered nurse (RN) who manages incoming GetWell Loop data. The members of the TBI care team use these data to determine which patients are experiencing persistent symptoms and their predominant clinical phenotypes, which in turn informs care plans and referrals.

Multidisciplinary Care Plans

At 4 weeks postinjury, described McCrea, a multidisciplinary board of brain injury medicine providers reviews patient data gleaned from the RN and the GetWell Loop app and to determine appropriate care plans. The team's patient-centered treatment features various care tracks to meet different needs. A "physician-only" track is designed for patients whose needs can be met by a PM&R provider. Other patients require care from both the PM&R physician and the neuropsychologist. A patient's primary symptom profile may warrant referrals to CBT, PT, occupational therapy (OT), and/or speech services. The team works to provide each patient with the specific care they need to have the best chance at full recovery, restoration of function, and a return to normal life activities.

DISCUSSION

Javier Cárdenas, professor and chief, Division of Sports Neurology, Rockefeller Neuroscience Institute at West Virginia University, moderated the discussion and asked about the role of non-revenue-generating positions on multidisciplinary TBI teams. Subsequent topics arose in response to comments and questions from participants.

Non-Revenue-Generating Positions

Cárdenas noted that non-revenue-generating staff positions, such as care coordinators, can support effective program functioning but asked

about the challenge of justifying their value since such roles do not directly generate institutional revenue. Shetty replied that funding these fundamental positions is a continual challenge. In addition to philanthropy, she uses program funds for this purpose with the justification that these positions result in downstream revenue. Every new patient appointment at the clinic results in multiple referrals, ranging from radiology to vestibular therapy to PT and OT. Barshikar remarked that his team has approached funding these positions as a mechanism for addressing physician well-being and burnout, noting that care coordination, accommodations and return-to-work documentation, and paperwork required for short-term and long-term disability insurance are time consuming. Removing these tasks from providers' workloads enables them to spend more time on direct patient care, he noted. Patients report on the usefulness of being able to contact the clinic social worker. Emphasizing the benefits that non-revenue-generating positions add to the clinic, Barshikar acknowledged that many settings focus on reimbursement and can be unwilling to fund ancillary positions.

McCrea stated that his program uses metrics such as reductions in hospital readmissions and return ED visits to demonstrate how non-revenue-generating positions add value. Philanthropy funds some of the cost of these positions. Acknowledging that multidisciplinary care is expensive, he highlighted an inherent, growing conflict between what health systems want and what patients indicate they want. McCrea questioned whether a model that is economically profitable but inconsistent with what patients want and need fulfills the mission of providing good health care. The challenge of building a world-class, best-practice, inpatient or ambulatory TBI program that is economically viable requires constant consideration.

TBI Center Accreditation Designation

Ramon Diaz-Arrastia, University of Pennsylvania, remarked that 25 years ago the stroke field faced similar challenges in funding comprehensive stroke care. Stroke can cause long-term debilitation, and comprehensive, postacute care was prohibitively expensive. This challenge shifted with the development of accredited comprehensive stroke centers, which generated competition among hospitals and fueled investment in attaining The Joint Commission's stroke center designation.[7] In turn, this led to a stronger negotiation position with insurance companies. When substantial resources were invested in multidisciplinary stroke care systems, insurance coverage expanded to include these centers. Diaz-Arrastia contended that the estab-

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[7] For further information on Joint Commission stroke certification programs, see https://www.jointcommission.org/what-we-offer/certification/certifications-by-setting/hospital-certifications/stroke-certification/.

lishment of designated or accredited TBI centers could similarly result in increased health care quality and hospital competition and investment.

Oyesanya noted a severe deficit in currently available follow-up care pathways for TBI. Services across a treatment continuum are needed to improve TBI outcomes, and these outcomes have wider implications for families and businesses, she said. The creation of a TBI center designation could encourage the expanded availability of needed comprehensive services. Hirschman commented on the apparent disconnection McCrea noted between what health systems value in TBI care and what patients and family caregivers feel is important. Policy changes can shift the metrics used to evaluate services, which in turn can influence investment decisions. Barshikar contended that consensus remains lacking on eligibility criteria for TBI services, thus such criteria need to be defined before the pursuit of accreditation designations.

David Okonkwo, University of Pittsburgh, maintained that the diagnosis-related group (DRG) classification for care compensation was a critical driver of the profitability of designated stroke centers. Attaining the status of designated stroke center creates a spillover effect, as the ability to treat acute stroke suggests the capacity to treat other conditions. The combination of center accreditation and DRG assignment to the episode of care creates an economic model that supports comprehensive care, he said.

Informing Care Plans with Phenotypic Data

Kathy Lee, Department of Defense, asked how phenotypic data from patients are translated into multidisciplinary models of care. McCrea noted that the data the GetWell Loop app collects between days 14 and 28 postinjury move beyond symptom tracking to the characterization of primary domains of symptoms, such as vestibular, cognitive, psychological, or headache or other somatic symptoms. In addition to indicating their symptoms and the effects these have on functioning, patients are asked to rate their top three areas of difficulty. The Froedtert-MCW TBI board uses these data to determine appropriate services and then uses their network of referral outlets to facilitate quick access to PT, OT, CBT, and other therapies. Acknowledging that these data are not as extensive as those provided by a detailed neuropsychological or multidisciplinary evaluation, McCrea remarked that the app enables high throughput and high volume in the early postinjury phase. He highlighted the variance in the needs of TBI patients; not all TBI survivors require extensive multidisciplinary care, nor do all those who need specialty care require every modality of therapy. Shetty added that the HSS Concussion Program uses an informal algorithm for patient risk stratification, and providers evaluate this information on a weekly basis through longitudinal visits to ensure that patients are triaged

appropriately. Similar to the GetWell Loop app, this process involves asking patients to rate their primary complaints. She highlighted the need for a more standardized process of determining TBI recovery phenotype.

TBI Program Sustainability

A participant asked about the role of economic analysis and standardized outcome datasets in program sustainability. Barshikar replied that UTSW has recently completed a quality improvement data collection project for the purpose of developing standardized datasets. Currently, the center is using an online survey to collect standardized data elements on all TBI patients, in addition to the data collected during patient intake. These efforts generate copious data, but given the numerous factors that can affect TBI outcomes—including comorbidities—the team has not yet developed a clearly defined outcome measure. He remarked that Texas state policy bolsters the sustainability of the UTSW program via an insurance code that prohibits health benefit plans from denying coverage of treatment for brain injury. This enables the UTSW programs to provide rehabilitation and therapies beyond what is afforded by plans in some other states.

Computerized Cognitive Testing

Given the shortage of neuropsychologists, a participant asked about the use of electronic tools for cognitive testing. Noting decades of use of computerized neurocognitive testing in sports and military settings, McCrea stated that the reliability, validity, and sensitivity of this technology is still inconsistent. He added that computerized cognitive testing functions as a data collection tool. As is the case with other data collection tools such as radiologic imaging, effective use of computerized testing requires meaningful interpretation of data to inform diagnosis and treatment planning. Thus, cognitive testing tools can increase the throughput of a neuropsychologist, but they do not replace the need for a provider who can interpret these findings and oversee treatment administration.

Common Data Elements

Noting his prior participation in the National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements initiative,[8] James Kelly, professor of neurology, University of Colorado, asked about the usefulness of combining patient-reported outcomes with data from diagnostic

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[8] More information about the Common Data Elements initiative is available at https://www.commondataelements.ninds.nih.gov/Traumatic%20Brain%20Injury (accessed June 22, 2023).

and prognostic assessments, perhaps from the Federal Interagency TBI Research (FITBIR) informatics system. Okonkwo explained that the initial funding for the Transforming Research and Clinical Knowledge in TBI study (known as TRACK-TBI) specified implementation of the TBI common data elements into research practice. At that point, FITBIR became a designated repository for federally funded TBI research, and federal grants stipulate that data must be submitted into FITBIR. The adoption of this concept into the clinical realm could enable the creation of a common language and drive advancements in the field. For example, consensus about molecular signatures of TBI and the terminology used to define this condition could enhance commonality in clinical designation and, in turn, could create more effective clinical care pathways.

Geoffrey Manley, University of California San Francisco, described the common data elements in FITBIR as iterative, noting the system is currently on a 3.0 version. Numbering at over 9,000, the common data elements must be pared down in order to identify those most useful for the clinical arena and for routine research. Standardization also enables improved demonstration of outcomes, and while the research required to develop standardization is expensive, so too are ED revisits, he contended. In parallel, health economics research can help determine the cost of hospital readmissions and ED revisits after TBI, which can then be used to justify the expense of routine TBI follow-up care. He drew a parallel to diabetes, which is expensive to manage, yet disease management reduces the long-term care costs over time. McCrea added that MCW has rebuilt its TBI clinic database to use common data elements for front-end demographics, acute injury characteristics, and outcome measures.

Early Steps in Establishing a Multidisciplinary TBI Clinic

Cárdenas asked about the components required in the initial stages of opening a multidisciplinary TBI clinic that could translate to other parts of the country lacking these services. Shetty replied that she began her program by networking with local schools, athletic trainers, coaches, athletic organizations, and other community groups. Giving talks about sports injury and TBI, she spread awareness about the need for care, and this awareness fostered the growth of the HSS Concussion Program. Barshikar emphasized the importance of connecting silos in TBI care and noted that the further development of standardization and outcome measures could support defragmentation efforts. Additionally, knowledge regarding moderate and severe TBI can be applied to injuries classified as mild. His clinic was part of a model system that was tracking outcomes for moderate and severe TBI, and he and his colleagues were able to extend the services in place for more severe cases to mild injuries. McCrea spotlighted the role

of TBI care leaders at MCW who helped champion the need for systematic follow-up of patients discharged from the hospital and applied their expertise to meeting this need.

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Achieving Effective Follow-Up Care Systems During the Initial Year Postinjury

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Key Messages Highlighted by Individual Speakers

- Addressing social determinants of health at the individual, interpersonal, community, and societal levels can improve outcomes after TBI. (Pappadis)
- A high incidence of blunt force head trauma among survivors of domestic violence creates a need for approaches that are both trauma and TBI informed. In treating survivors of domestic violence, providers need to consider how immediate and longer-term needs and consequences of violence may affect a survivor's ability to engage in TBI follow-up care. (Nemeth)
- Currently, state and community-based service delivery systems exist to help connect TBI survivors with services to support recovery. One example is the Alabama TBI resource facilitation program, which includes care navigation and coordination services for patients of all ages with mild to severe head injuries. These existing state and community programs can serve as models for replication elsewhere in the country. (Turner, Wolfkiel)

NOTE: This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

The fourth session of the workshop featured examples of programs designed to address care needs following TBI, including social, emotional, and structural factors that influence recovery. John Corrigan, emeritus professor, Department of Physical Medicine and Rehabilitation and director, Ohio Valley Center for Brain Injury Prevention and Rehabilitation, The Ohio State University (OSU), opened the session and highlighted that the 2022 *Traumatic Brain Injury: A Roadmap for Accelerating Progress* report stated that fully addressing TBI requires a framework that extends beyond a medical model of injury to include personal, social, and environmental factors that affect recovery (NASEM, 2022). The report included recommendations that health care systems connect with (1) partners outside of health care, (2) expertise in domains that contribute to health equity, and (3) community members and institutions with which patients interact. Moreover, the report recommended that equity should be institutionalized in the infrastructure of organizations and in their community partnerships.

ADDRESSING SOCIAL DETERMINANTS OF HEALTH THAT AFFECT TBI RECOVERY

Monique Pappadis, associate professor in the Department of Population Health and Health Disparities, University of Texas Medical Branch, discussed the effects of social determinants of health on TBI recovery at the individual, family, community, and societal levels. Social determinants of health exist in five major domains: economic stability, education, health care access and quality, neighborhood and built environment, and social and community context. Health disparities are preventable historical or current differences in burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations. Many TBI patients experience these disparities, she said. A research framework developed by the National Institute on Minority Health and Health Disparities examines how domains of influence—biological, behavioral, physical/built environment, sociocultural, and health care system—operate at the individual, interpersonal, community, and societal levels (NIMHD, 2017). Facilitators of, and barriers to, health within each domain can change over time.

Pappadis outlined numerous social factors that can affect TBI recovery at the individual level. Race and ethnicity are social constructs with effects ranging from personal interactions to the structure of systems—influencing who has access to health care—and have been shown to result in health disparities (Lequerica et al., 2023). Education and socioeconomic status also affect recovery patterns. For example, food insecurity creates barriers to adequate nutrition for good health that can negatively affect well-being after a TBI (Driver et al., 2019). Lack of transportation affects an individual's ability to follow a recommended care plan. Pappadis noted that

many of the patients with whom she has communicated had missed follow-up appointments because of transportation challenges. In working with Spanish-speaking persons with TBI, she has found limited English language proficiency to be a major barrier to accessing care and achieving full recovery (Pappadis et al., 2022).

Many health care settings do not provide care in a culturally competent manner and lack appropriate translation services and information accessible to all individuals (Arango-Lasprilla, 2012). Health literacy plays a role in outcomes, warranting efforts to both increase health literacy and improve the information provided to patients as well as their access to appropriate health care. To address individual-level social determinants of health that influence TBI treatment and recovery, she suggested developing culturally relevant interventions, addressing discrimination, providing supports and resources to improve health and well-being, and using technology to better monitor patient health.

Families play a large role in TBI recovery, and supporting the family unit can bolster treatment plans, said Pappadis. Interpersonal social determinants of health that influence TBI recovery include the caregiving burden, family dysfunction, decreased social networks, education and employment of family members, interpersonal discrimination, access to health providers, and patient–provider interactions (Baker et al., 2017; Gordon et al., 2015; Sodders et al., 2020; Trexler et al., 2016). Family supports to enhance recovery can include direct services to family members, resource facilitation at the institution and state levels, and interventions to improve and implement culturally humble practices. Pappadis remarked that in her work connecting TBI survivors with needed services, she has found that many institutions have not developed sufficient community partnerships and therefore lack the capacity to make appropriate referrals to address patient needs related to social determinants of health.

Pappadis emphasized that community factors such as environment, community, neighborhood, crime, poverty, and safe and stable housing can affect a TBI patient's ability to adhere to a treatment plan (Budnick et al., 2017; Moore et al., 2016; Pappadis et al., 2012; Sander et al., 2011). Strategies to address community-level social determinants of health include service coordination and establishing partnerships with community agencies, connecting TBI patients and their families to needed services, advocating for housing programs and policies to improve safety, and creating community-based intervention programs.

At the societal level, social determinants of health include laws and policies that influence the behaviors of patients, families, providers, organizations, payers, and governments. For example, most states have Medicaid Home and Community-Based Services waivers in place to provide care and services to persons with disabilities and older adults, but only about half of

these waivers include TBI-specific services. Changes at the policy level could increase institutional capacity to provide appropriate care, which in turn could enable providers to improve the care they offer, leading to improved outcomes after TBI.

FUNDAMENTALS OF TRAUMA-INFORMED CARE FOR VULNERABLE POPULATIONS

Julianna Nemeth, assistant professor of Health Behavior and Health Promotion, Ohio State University College of Public Health, discussed the fundamentals of trauma-informed care for vulnerable populations. As a scientist focused on health equity interventions, she conducts community-based participatory action research to help survivors of interpersonal violence with chronic brain injuries change health risk behaviors and access safety, health, and social services. Her early-career direct advocacy work in domestic violence and sexual assault programs took place in settings including courtrooms and emergency departments. Upon recognizing a need for changes in the interpersonal violence evidence base, she moved to academia to conduct research with violence survivors.

Violence is a social and structural determinant of health, Nemeth emphasized, and trauma from interpersonal violence is pervasive. For instance, one in three women will experience severe violence from an intimate partner in her lifetime; the rate for men is only slightly lower at one in four. Populations with lower levels of access to social and structural resources supporting health are simultaneously at increased risk of experiencing violence, including TBI. The Substance Abuse and Mental Health Services Administration defines individual trauma as "an event or circumstance resulting in physical, emotional, and/or life-threatening harm that has lasting adverse effects on the individual's mental, physical, emotional, social, and/or spiritual well-being" (SAMHSA, 2022). Providers of advocacy services for survivors of violence understand that current traumatic events occur within a larger context that includes historical and intergenerational trauma and social determinants of health.

Because trauma-informed care is standard practice for working with survivors of violence, agencies that focus on this population have adopted trauma-informed practice frameworks, Nemeth explained. These frameworks use a flexible approach to service delivery that centers on the needs of the client. Adopting this approach can require changing organizational practices, policies, and procedures (SAMHSA, 2014). Trauma-informed practice entails efforts to avoid retraumatizing survivors by acknowledging the widespread effect of trauma on individuals' lives, recognizing signs and symptoms of trauma, and responding with sensitive services that integrate trauma knowledge into practice. Many survivors of violence engage in

high-risk behavior and struggle to access and find success with health and safety services. Noting a link between domestic violence, sexual violence, childhood abuse, community violence, and suicide, she underscored that high-risk behaviors can be life threatening.

TBI and Interpersonal Violence

Nemeth remarked that brain injury considerations are infrequently applied to interventions for survivors of domestic violence, despite the higher risk of TBI among this population. To address this need, OSU uses a federally funded, public health planning process to help domestic violence agencies improve service access for survivors facing mental health and/or TBI challenges. Nemeth and colleagues used data from a needs assessment—conducted with 46 survivors of domestic violence receiving services at five programs across Ohio—to inform intervention design. The assessment revealed that 72 percent of survivors accessing services had experienced blunt force head trauma—half of whom had been struck in the head more times than they could accurately count—and 80 percent had experienced strangulation with subsequent alteration in consciousness. The head and neck are the most common target sites for domestic violence; 44 percent of participants reported that their first experiences of violence toward their head or neck included concurrent blunt force head trauma and strangulation. The assessment also inventoried the current physical, emotional, and cognitive symptoms that the survivors of domestic violence were experiencing, including seizures (15 percent of participants), anger or rage (61 percent), memory issues (72 percent), drug or alcohol concerns (13 percent), and thoughts of suicide (11 percent).

Approaches to Care Informed by Trauma and TBI

Despite the high rate of head trauma and associated symptoms among survivors of domestic violence, advocates and survivors who participated in the research were largely unaware that repeated head trauma and strangulation could result in brain injury, reported Nemeth. She recounted a survivor, who tried to end her life 10 years after experiencing strangulation and TBI, who said, "If the right person had the right knowledge, this all could have been avoided." In response to such insights, OSU and the Ohio Domestic Violence Network created a trauma- and brain-injury informed framework—the CARE approach—that considers social and structural determinants of care that affect the daily lives of violence survivors (see Box 4-1).[1]

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[1] More information about the CARE program and Ohio Domestic Violence Network is available at https://www.odvn.org/brain-injury/ (accessed June 29, 2023).

BOX 4-1
CARE Approach: Brain-Injury-Informed
Framework for Trauma-Informed Care

- *Connect* with survivors by forming genuine and healthy relationships.
- *Acknowledge* that head trauma and mental health challenges are common, provide information and education to survivors, and identify short- and long-term physical, cognitive, and emotional consequences.
- *Respond* by accommodating needs related to traumatic brain injury, strangulation, and mental health challenges, and provide effective, accessible referrals and advocacy for individuals who need additional care.
- *Evaluate* accommodations and referrals, and touch base regularly to see if adjustments need to be made.

SOURCE: Presented by Julianna Nemeth, The Ohio State University, May 9, 2023.

The approach focuses on accommodations and accessibility and is integrated into a package of service provider tools.

As a component of the CARE approach, connecting refers to service providers connecting with patients to extend their understanding beyond injury and abuse to a survivor's personal priorities and motivations, learning what matters and is meaningful to each individual. For example, a TBI patient experiencing domestic violence may have needs that supersede follow-up care appointments. Therefore, meeting both the immediate and longer-term needs of survivors can facilitate recovery. Nemeth reported that many survivors of violence have had negative past experiences while receiving health care; connection can provide reassurance, consistency, and a context for trust.

The second step of the CARE approach is acknowledging the effects of both trauma and TBI, said Nemeth. Acknowledgment in advocacy practice involves understanding that (1) head trauma and mental health challenges are common in survivors of violence, and that (2) brain injury and social determinants of health affect service engagement. In health care, acknowledgment refers to recognizing that domestic violence, trauma, and social determinants of health will affect follow-up care after TBI. Numerous short- and long-term consequences of experiencing violence and head trauma—including substance use, suicidal ideation, and executive dysfunction—are recognized as common among survivors of violence. Executive dysfunction can affect survivors' ability to access safety and basic services and to fully engage in both daily activities and in life-saving processes. Many survivors do not attend follow-up care

appointments, criminal justice proceedings, or counseling sessions despite the high stakes that may be involved (for example, maintaining custody of their children). She suggested that rather than framing a survivor's lack of follow through as unwillingness, executive dysfunction may be the cause. Reframing why a survivor "will not" engage in follow-up care to asking why she "cannot" can enhance problem solving in both advocacy and health care, she added.

Responding to survivor needs is the third step of the CARE approach. Providers should offer accommodations and effective, accessible referrals for an individual's needs related to TBI, strangulation, and mental health challenges. Offering support tailored to a person's unique needs creates opportunities to address potential barriers to success. Nemeth explained that the final step in the CARE approach is to evaluate whether the accommodations and supports have been effective in meeting a survivor's needs, then determining whether changes are needed to increase effectiveness.

To facilitate the integration of connection, acknowledgment, response, and evaluation into practice, the Ohio Domestic Violence Network and OSU developed CARE tools distributed to agencies working with survivors of violence, as well as offering brief trainings on brain injury and mental health issues to enable advocates to discuss these topics with survivors of violence in nonmedical ways. During the first year of implementation, agencies used the CARE tools in courtrooms, shelters, and counseling centers, said Nemeth. An assessment indicated that use of the CARE tools strengthened agency-wide, trauma-informed practices to address head trauma, strangulation, mental health, substance use, and suicide (Nemeth et al., 2023). Additionally, implementation of the CARE framework facilitated survivor empowerment and increased the sense of support that staff felt in providing trauma-informed care. Staff reported feeling empowered to better address brain injury after being equipped with the language and tools included in CARE (Kemble et al., 2022). Staff members using CARE tools are also more likely to reframe survivor behavior as "cannot" rather than "will not," she said, and thus are more likely to provide survivors with accommodations, structural and functional supports, and self-help efforts.

Community-Based, Trauma-Informed Systems of Care

Increasing survivor engagement in follow-up care can be a challenge for advocates working in medically disconnected, community-based organizations, remarked Nemeth. The high rates of brain injury among survivors of violence warrant efforts to better connect systems of TBI response and treatment to community-based organizations working with this population. To that end, OSU is soliciting community input from safety, justice, and social service organizations serving survivors of violence to translate

research on violence-based chronic brain injury into services for survivors. Thus far, OSU has hosted two large gatherings of community-based organizations and survivors of violence to cocreate models and practice processes with communities.

DESIGNING AND ACCESSING APPROPRIATE
COMMUNITY SERVICES

Rebeccah Wolfkiel, executive director, National Association of State Head Injury Administrators (NASHIA), explained that her organization is a national nonprofit trade association that assists state governments in creating systems of care to support people living with brain injuries. NASHIA contributes technical assistance, training, networking, and advocacy to state efforts to build TBI service capacity. Most states have a state-level program dedicated to this issue; however, the programs' services, policies, and location within government vary—for example, they can be housed in vocational rehabilitation agencies, aging and independent living services, behavioral health services, public health, human services, or state universities. The department in which a state brain injury program is located influences its priorities and the services it offers.

States use a variety of resources and funding sources to build programming and systems of care for TBI, said Wolfkiel. Among federal programs accessible to state governments, the Administration for Community Living delivers a state grant program for TBI that awards competitive grants to approximately 30 states.[2] These infrastructure-building grants fund state-level positions focused on creating systems of care for brain injury and partnerships with other relevant agencies. Many states also dedicate budget line items to TBI systems of care, she added.

Neurological Resource Facilitation

Wolfkiel emphasized that resource facilitation, care coordination, and resource navigation services help people with TBI access available community resources, such as vocational rehabilitation, housing, and transportation support, and contribute to improved long-term outcomes. Most state programs feature a resource navigator who conducts a needs assessment to make a holistic determination and prioritize areas of need, then identifies the top three community service needs that are most likely to help an individual return as close to their baseline as possible. Length of services differs between states—ranging from months to years or even indefinitely, in some

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[2] For information on the ACL's State Partnership Grant Program, see https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi (accessed July 27, 2023).

states—and outreach frequency is typically biweekly or monthly. Alabama, Colorado, Iowa, and Minnesota have mature neurological resource facilitation programs that have been in operation for over 3 decades, she noted.

In 2000, the U.S. Department of Health and Human Services funded the Brain Injury Association of America (BIAA) to create a best practices guide on resource facilitation for individuals with brain injury (Connors et al., 2001).[3] State facilitation approaches vary widely, she noted, but are often flexible and person centered. Some states use a regional approach in lieu of a statewide program to contend with a lack of resources. Programs that provide a limited range of agency-specific services typically direct patients with additional needs to state-level affiliates of BIAA or the United States Brain Injury Alliance. She noted that active referrals—in which the medical discharge planner contacts an advocacy organization on behalf of the patient—are more beneficial than simply providing patients with the organization's contact information.

The services TBI survivors most frequently seek out via resource facilitators are support groups and physical, occupational, and/or speech therapy; other common needs include in-home care, assistive technology, housing support, and a host of other services designed to assist individuals in returning to school or work. Because of the variability of programs across states, NASHIA and the Moody Foundation have partnered to conduct a Delphi-based consensus process, bringing together a group of national experts in the field to determine the common components that provide the most benefit for people using resource facilitation programs.[4] Taking place in 2023, the process will also explore outcome measures and work toward establishing a gold-standard model that states can replicate. Wolfkiel highlighted growing research on the efficacy of neuro-resource facilitation, particularly in vocational and return-to-school settings (Davis et al., 2018; Seymour et al., 2008; Trexler and Parrott, 2022; Trexler et al., 2016).

ALABAMA TBI SYSTEM OF CARE

April Turner, director of Traumatic Brain Injury Programs within the Alabama Department of Rehabilitation Services, provided an overview of

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[3] This manual outlines elements including assessment, planning, identification, negotiation in prioritizing services, monitoring, reassessment, outreach, education and training, and emotional support and advocacy. Best practices are guided by the principles that facilitation is individualized, accessible, holistic, effective and valued, participant-driven, flexible, and builds community partnerships.

[4] The Delphi technique is a systematic, consensus-development method of forecasting using the opinions of a panel of experts.

the Alabama system of care for TBI,[5] which serves individuals with head injuries ranging from concussion to severe brain injury. The system is partially funded by federal grants and features resource navigation services, an advisory council, a task force, a trust fund board, and a head and spinal cord injury registry. This newly created statewide navigation system receives referrals from hospitals, the state trauma registry, medical providers, advocacy organizations, community agencies, website inquiries, and state departments including mental health, senior services, veteran affairs, and vocational rehabilitation. Navigators funded by federal TBI grants staff a toll-free helpline and respond to referrals with a range of resources and services offered to individuals at no cost. These include education and training, online screening, resource facilitation, referral, and case and pediatric/adult care coordination among a variety of public and private community providers, such as cognitive remediation, neuropsychological testing, therapeutics, socialization, suicide prevention, and behavioral health services. In partnership with NASHIA, Alabama has also conducted statewide needs assessments, a state TBI plan, increased advocacy, and public awareness of TBI.

The Pediatric and Adult TBI Care Coordination program uses master's-level social workers and rehabilitation counselors to provide in-home services within 2 years post-injury, Turner noted. Care coordinators connect individuals with service providers and resources (e.g., referrals, support groups, telehealth, vocational rehabilitation services) to help them achieve their specific goals, with the overall aim of reintegrating individuals in school, employment, and community settings. In 2022, the Alabama TBI system of care received 6,874 referrals for TBI and spinal cord injury from Alabama Hospitals including all Level 1 trauma centers. Turner noted that of those referrals, 526 individuals received resource facilitation and referral services, 383 children entered the Pediatric Care Coordination program, 378 people received support from an adult care coordinator, and 211 individuals engaged in information, education, and training offerings. Alabama's TBI resource facilitation and care coordination programs have been in place for years, and Turner noted that they have continued to improve program models by creating a TBI navigation and helpline system to increase access to community services for individuals with head injuries, their families, and care providers.

DISCUSSION

Corrigan moderated the discussion. He began by asking panelists how soon after a brain injury should professionals address needs related to

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[5] More information about Alabama TBI services is available at https://www.alabamatbi.org/ and https://rehab.alabama.gov/services/vr/tbi (accessed July 8, 2023).

social determinants of health, domestic violence, trauma, and community services? Subsequent topics arose in response to comments and questions from participants.

Time-Sensitive Social Determinants of Health Support

In response to Corrigan's opening question, Turner emphasized that promptly addressing these issues facilitates easier care transitions and supports recovery. Therefore, the Alabama model aims to attend to these issues within the first 2 years postinjury, although services can extend beyond that time frame. Referrals enter the trauma registry via hospitals, local doctors, and Level 1 trauma centers, and the program uses established relationships with hospitals to ensure that hospitals' floors and discharge areas make referrals. Care coordinators guide services and remind patients of follow-up appointments. Wolfkiel added that some models feature a hospital employee responsible for making active referrals to community resources, thereby shortening the timeline between discharge and service engagement. Nemeth stated that these issues should be addressed as quickly as possible for all patients because they can be critically important for survivors of violence. Safety is paramount for survivors of intimate partner violence, human trafficking, or sexual assault. Furthermore, survivors of violence are often isolated from support networks. Therefore, immediate efforts to address social determinants of health and any barriers to accessing both health and safety services are essential for this population. Pappadis concurred that social determinants of health should be addressed early and support needs should be reassessed regularly, as numerous factors influence recovery and circumstances can change over time.

Care Coordination Funding and Caseloads

A participant remarked that care coordinators and patient navigators contribute their expertise in social issues, regulations, and laws when providing input to clinicians. She asked how best to advocate for the types of successful, well-used programs presented in this session, noting that such programs often do not receive adequate funding despite the social benefit their services provide. Wolfkiel responded that NASHIA advocates for funding for these programs and that some states use federal funds, including Administration for Community Living TBI grants, for this purpose. She added that additional cost/benefit research is needed, as data indicating the long-term benefits associated with these programs would strengthen requests for increased federal funding.

In response to a question about the average caseloads of navigators, Wolfkiel stated that navigators in most states serve 50–65 patients, with

some states reaching navigator caseloads as high as 175 individuals. Turner noted that the Alabama program stretches an operating budget of approximately $1 million across care coordination services, advocacy, and independent living. Care coordination positions in Alabama are funded via fines imposed for driving under the influence, she said. These monies fund four care coordinators for the entire state, creating coordinator regions so large as to necessitate 3-hour drives to meet with clients in their homes. The governor has included line-item funding in the state budget that will add two additional care coordinators and reduce caseloads to approximately 40 clients per coordinator, she said. Turner added that Alabama used TBI grant funding from the Administration for Community Living to develop its resource model in which *navigators* handle resource facilitation calls, thus relieving care coordinators of this responsibility and enabling them to dedicate more time to home visits.

Incorporating Social Determinants of Health into Guidelines

Mark Bayley, professor in the Division of Physical Medicine and Rehabilitation, University of Toronto, asked about embedding social determinants of health considerations into practice guidelines. Pappadis suggested applying the lens of vulnerable populations to the process of developing clinical care guidelines for TBI to identify whether specific recommendations would have limited accessibility or applicability for certain subgroups. Gathering input from TBI survivors from vulnerable populations is the best way to incorporate their needs into guidelines, she added. Nemeth stated that guidelines should explicitly name vulnerable and special subpopulations, and that experts working with these subpopulations should be engaged in the guideline development process. Bringing together expertise from different areas can create guidelines that better meet the needs of TBI survivors. Turner noted that most states have advisory councils, and that these can serve as a mechanism for soliciting guidance and input from individuals with lived experience with TBI.

Program Attrition

Regarding client attrition, Turner noted that a service gap can occur between referral and the initial care coordinator home visit. However, once the care coordinator establishes service with an individual, very few clients in the Alabama system disengage from services before they have achieved their goals. She attributed this to the warmth and focus on relationships with which care coordinators approach service provision, adding that many clients continue to stay in touch with their coordinators for years or even decades after services have ended. Corrigan remarked that in-person ser-

vices such as those provided by Alabama's system of care tend to experience lower levels of dropout, whereas services provided through telephone- or remote-based models are more likely to be periodic in nature with larger service gaps. Such trade-offs will need to be considered when designing systems of TBI follow-up care and services.

TBI and Elder Abuse

In response to a question about whether TBI research has been conducted with older survivors of abuse, such as people living in nursing facilities, Nemeth emphasized that violence typically targets vulnerable populations. Older adults, children, survivors of natural disasters, immigrants and refugees, people with disabilities, and individuals dependent on others for care are more vulnerable to experiencing violence than the general population. She remarked that more research and efforts to engage vulnerable populations in community services are needed to ensure that those at greatest risk for acquired TBIs are receiving services and resources. Pappadis commented that the University of Texas has received funding to explore the intersection of elder mistreatment and TBI; she is currently researching how best to improve screening and service referrals to ensure that older adults are in safe environments.

Fostering Community Partnerships

Corrigan asked about the readiness of community agencies to partner with health care systems. Wolfkiel replied that community agencies frequently operate via collaboration and partnerships, and are therefore primed to contribute to such endeavors. Turner commented that the Alabama patient navigation system has expanded twofold over its lifetime, demonstrating both the need for these services and the community's willingness to help meet the need. She noted that Alabama's TBI system of care has also partnered with federal and state departments of veterans affairs to ensure that veterans with TBIs are linked to care. She reflected that additional funding for TBI services could enable further program expansion to serve a greater number of TBI survivors.

Nemeth commented that community organizations are typically open to partnerships but may not have the workforce capacity to take on additional initiatives. The COVID-19 pandemic led to an increase in domestic violence and head trauma, taxing the capacity of programs with limited budgets. Innovative methods of partnership, outreach across states, and enhanced funding for health services for survivors of violence can increase engagement with potential community partners. Noting that community partners often have inadequate resources to meet the needs they are work-

ing to address, Pappadis acknowledged the potential challenge that new partnerships can generate additional clients needing services. However, developing partnerships among multiple community organizations addressing similar needs can also help to distribute the additional client load across groups, she said.

A participant agreed that creative problem solving can enable collaborative relationships within underresourced systems. For example, she worked at a county hospital in Tennessee that contributed to a community partnership by providing a free office space to a care coordinator and obtaining permission from the state to share patient information with her. This coordinator sent letters to hospitalized patients so they had immediate access on their return home to information about housing, rehabilitation, Medicare and Medicaid, and support groups. Corrigan added that the resource facilitation program in Ohio contracts an Ohio Domestic Violence Network employee to enable ongoing collaboration for referred individuals who have needs related to TBI and violence. Turner shared that coordination across state systems can also be useful to address services for TBI patients. For instance, the neighboring states of Alabama and Tennessee collaborated to address needs in which patients from a Tennessee-based hospital near the border have been referred to the Alabama TBI system of care.

Wolfkiel remarked that community services agencies often receive less public and policy attention than medical and research communities, despite the important roles they play, and that providers and researchers should recognize and advocate for TBI-relevant community services. Nemeth highlighted that funding via the Violence Against Women Act primarily supports criminal justice responses to violence versus health justice responses.[6] Notwithstanding the higher rates at which survivors of violence use emergency health services, health has not been a focus of federal funding for this population. She added that some survivors of violence are also members of populations that experience higher rates of incarceration and police encounters; therefore, they may be reluctant to participate in responses focused largely on criminal justice but may be more inclined to engage in services to meet health needs. Health justice work would also benefit from further advocacy and funding, she suggested.

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[6] *Violence Against Women Act of 1994*, Public Law 103-322, 103rd Cong., 2d sess. (September 13, 1994).

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Improving Systems of Follow-Up Care: Perspectives on the Roles of Certification, Reimbursement, and Information Management Systems

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Key Messages Highlighted by Individual Speakers

- Lessons from development of the stroke center certification program can be applied to advance TBI systems of care. The successful adoption of the stroke certification program substantially increased the availability of comprehensive stroke care. (Baker)
- The creation of financial incentives tied to targeted measures of provider performance could help address gaps in the provision of TBI follow-up care. (Seabury)
- Technology platforms can help provide predictive capability and customized, convenient online patient experiences to improve TBI follow-up care. (Wright)
- TBI care system design needs to consider issues of equity to avoid inadvertently exacerbating health disparities. (Baker, Seabury)

NOTE: This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

The fifth session of the workshop explored potential mechanisms for expanding the scope, scale, and sustainability of TBI follow-up care programs, including the roles of center certification, financial incentives, and

technology platforms. These examples illustrate different types of enabling mechanisms: certification programs can help standardize elements of care and encourage institutional adoption of certification requirements; financial incentives influence how health care programs and systems navigate competing priorities; and technology and data management platforms can assist in data collection, integration, and learning to enhance care. Cross-cutting issues in enhancing learning health systems for TBI, including the roles of information integration and coverage for TBI care and rehabilitation, are areas of ongoing interest to the Forum.

APPLYING LESSONS FROM STROKE CENTER CERTIFICATION TO TBI CARE

David Baker, executive vice president for Healthcare Quality Evaluation and Improvement, The Joint Commission, discussed the stroke certification program as a potential model for encouraging a more comprehensive TBI system of care. In 2005, the Brain Attack Coalition (BAC) published a consensus statement describing elements of stroke systems of care that included primary stroke centers, comprehensive stroke centers, and the essential structures and processes of these facilities (Alberts et al., 2005). Guided by BAC-defined criteria, stroke experts partnered with The Joint Commission and the American Heart Association to design a stroke certification. Initially, the certification featured two levels of care: primary and comprehensive. Once the certification program became established, emergency medical system providers nationwide used it in determining triage transportation decision rules, which in turn created a financial driver for hospitals to become certified. Given the lucrative nature of many stroke procedures, he noted, becoming a destination for ambulances transporting suspected stroke patients carried a financial incentive for hospitals. To date, over 1,600 hospitals have attained stroke center certification from The Joint Commission.

The certification system has evolved over time, Baker noted. As experts began to recognize the need for faster treatment, particularly in regions with long transport times, The Joint Commission created an additional stroke certification. The acute stroke-ready hospital certification applies to programs that are able to begin thrombolytic treatment and rapidly transport patients to a higher level of care, a process known colloquially as "drip and ship." The thrombectomy-capable stroke center certification was created after evidence demonstrated that mechanical thrombectomy for strokes caused by large vessel occlusions dramatically improves outcomes. In addition, The Joint Commission developed a set of process and outcome measures to drive improvement and to prove that stroke centers—particularly comprehensive stroke centers—achieved improved

patient outcomes. Baker outlined numerous lessons learned from the stroke center certification development process that apply to TBI systems of care (see Box 5-1). These lessons may be helpful as the TBI community considers strategies to enhance care and follow-up after TBI, Baker concluded.

THE ROLE OF FINANCIAL INCENTIVES IN TBI FOLLOW-UP CARE

Seth Seabury, director of the Keck-Schaeffer Initiative for Population Health Policy and associate professor in the Department of Pharmaceutical and Health Economics, University of Southern California (USC), discussed how financial factors affect health care access and the role that financial incentives could play in increasing provision of, and access to, TBI follow-up care. A study from the Transforming Research and Clinical Knowledge in TBI (TRACK-TBI) consortium showed that nearly half of TBI patients with Glasgow Coma Scale (GCS) scores of 13–15—indicating a mild TBI—with significant postconcussive symptoms were not seen by a medical practitioner within the first 3 months of injury (Nelson et al., 2019). A person suffering from TBI symptoms might not receive care because of such issues as poor care coordination, lack of awareness of treatment options, techno-

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BOX 5-1
Applying Lessons from Stroke Center Certification to TBI Care

- Identifying best practices, gaps in care, and research demonstrating that the absence of recommended care leads to poorer outcomes.
- Using communication strategies to increase public awareness and to frame the issue as a matter of public health to generate community and payer support.
- Clearly designing the desired system of care, including the resources required at each level of care to achieve optimal outcomes and how the levels integrate and collaborate with one another.
- Establishing a single standard of care for all patients with TBI; generate public understanding that concussions are brain injuries to support efforts to design, implement, and modify the system of care to meet the established standard.
- Designing systems from the outset to promote equity and mitigate disparities (e.g., build access points to tertiary and quaternary medical centers, integrate telehealth and digitally enabled care).
- Identifying drivers of return on investment for providers within the system, including TBI follow-up care and rehabilitation services (e.g., engage payers using Medicaid and bundled payments for care).
- Measuring care and outcomes to prove that it is possible to provide high-quality and equitable care at scale.

SOURCE: Presented by David Baker, The Joint Commission, May 9, 2023.

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logical hurdles, or insufficient financial incentives for programs that could provide follow-up care. Numerous examples demonstrate the influence of financial incentives on behavior in health care, Seabury said. For instance, research shows that patients are less likely to adhere to prescribed medication regimes when they face greater cost-sharing. Furthermore, Seabury noted, physicians are more likely to accept patients with generous insurance plans and providers direct more resources toward lucrative procedures and treatments. This tendency is evident in the relationship between increases in reimbursement for specific procedures and subsequent increases in frequency of performing those procedures. Given that financial incentives affect behavior throughout the health care system, understanding such incentives can aid in identifying potential solutions to increase rates of TBI follow-up care, he said.

Financial Status of TBI Populations

On average, the population of TBI survivors is poorer and has lower levels of health insurance coverage than the general population, said Seabury. People who have experienced a TBI are almost twice as likely to be uninsured (18 percent) than the general population (10 percent) (Seabury et al., 2018). Moreover, TBI survivors are less likely to have private insurance, with 56 percent having private coverage compared to 68 percent of the general population. Whereas 33 percent of Americans have an annual income greater than $50,000, only 26 percent of people with TBI attain income at that level. Seabury acknowledged that these statistics come from the TRACK-TBI study, which was not nationally representative and therefore may not reflect the lived experience of all TBI patients. Nonetheless, these statistics are reflective of much of the adult civilian nonsports population who have experienced TBI.

Seabury noted that the economic disadvantages faced by a significant portion of TBI patients can pose barriers to accessing follow-up care: both lower insurance rates and lower income decrease the likelihood of receiving appropriate care. Researchers explored these access barriers by randomly calling multiple ambulatory care clinics while posing as patients (Asplin et al., 2005). They told the clinics they had been recently discharged from the emergency department (ED) with instructions to receive follow-up care within 1 week. Each clinic was contacted twice by the same researcher, who would claim to have private insurance on one call and claim to have Medicaid or no insurance on the other. Calls placed by the same caller to the same clinic were more likely to result in an appointment within 1 week if the caller claimed to have private insurance versus Medicaid or no insurance. However, callers claiming to be uninsured but able to pay out of pocket in full for the appointment were just as likely to be scheduled for

an appointment as callers with private insurance. This indicates that the likelihood of receiving an appointment is associated with the ability to pay, rather than any contractual obligation with insurers, Seabury noted.

Creating Incentives for TBI Follow-Up Care

Barring the ability to increase the incomes of the TBI patient population, methods for financially incentivizing follow-up care for TBI within existing U.S. health systems could help address gaps, said Seabury. Such incentives often fall under the categories of "value-based care" or "pay-for-performance." Such care involves financial incentives or disincentives targeting improvement of specific measures of provider performance or health care outcomes. For example, a hospital readmission penalty can serve as a disincentive. Using financial incentives and disincentives to improve rates of TBI follow-up care would entail data collection efforts, such as tracking the care that TBI patients receive and their outcomes. This data collection could be approached by creating quality metrics relevant to TBI follow-up care, such as the percentage of patients discharged from the ED that receive appropriate TBI educational materials, or the percentage of patients with a positive finding on a head computed tomography (CT) scan that receive care from a TBI specialist within 90 days. Currently 30–40 percent of mild TBI patients with a positive CT finding do not see a provider, Seabury noted (Seabury et al., 2018). Such metrics could be tied to financial bonuses or penalties for hospitals or health plans to drive desired behavior change.

Attention to implementation is key to ensuring that financial incentives result in intended changes, said Seabury. Pay-for-performance or value-based purchasing systems do not work effectively unless appropriately designed. Systems implementing financial incentives for quality care need to determine who will be penalized or rewarded based on the quality measures used and to consider in their designs the types of health equity considerations raised during prior sessions of the workshop. Furthermore, the value case and sustainability of existing services needs to be considered, as well as how to make value cases for the uptake of new innovations. Insurance or payer reimbursement is a significant consideration throughout the care system. Seabury pointed to the pharmaceutical industry as an example in which companies have made effective value arguments leading to coverage and reimbursement for drugs with expensive up-front prices.

THE ROLE OF TECHNOLOGY IN OPTIMIZING TBI FOLLOW-UP CARE

David Wright, founder and chief executive officer, Disruptive Innovations, discussed the use of technology platforms to improve the patient

experience and uptake of follow-up care. He used the example of an actual health system that contains over 400 practices, 14 hospitals, more than 9,000 physicians, 8 different electronic health record (EHR) platforms, and hundreds of software applications. The resulting operational inefficiency creates challenges regarding patient access, siloed care, data-driven decision making, care coordination, and quality of care. Technology platforms can help address such issues, supporting development of a health care system in which a patient's record is not lost during transfers between specialties or practices and promoting better follow-up care, he said. The COVID-19 pandemic also created new demands on health systems and created an opportunity for increased innovation, including in enabling technology platforms. Although many health systems made efforts to use technology to better meet the demands of the pandemic, he said, many of these efforts involved automated patient interfaces that do not provide continuity throughout the patient experience life cycle. However, automation will only increase the use and effectiveness of follow-up care for TBI if it successfully engages patients.

Wright remarked that technology can be used to create a patient experience that features a consistent context across interactions, is personalized to a person's needs and progress, and enables communication with a provider 24 hours a day, 7 days a week via the individual's preferred mode of communication. He noted that Amazon, Walgreens, and other retailers are building patient experience spaces within the cloud environment, and customers will likely interact with such systems because they have been designed for ease of use. At the onset of the COVID-19 pandemic, Disruptive Innovations created a patient experience optimization module that considers the people, process, technology, and methodology surrounding the patient experience life cycle throughout the continuum of care, and this type of module has potential application to TBI care (see Box 5-2). Wright noted that cross-training and properly implementing knowledge management programs can also expand the ability of care coordinators to operate beyond one specialty.

DISCUSSION

Tolu Oyesanya, Duke University School of Nursing, moderated the discussion and posed an opening question on key strategies related to scalability, reimbursement, and innovation to improve TBI care and follow-up. Subsequent topics arose in response to comments and questions from participants.

BOX 5-2
Patient Experience Optimization Module

Disruptive Innovations' patient experience optimization module extends throughout the continuum of care. The module's front-end functions include streamlined scheduling, a patient answer center, financial clearance to prevent care denials, preregistration, front-end payment, appointment reminders, and clinical support and triage. The module aims to facilitate ongoing support, personalized follow-up care, and advocacy. The designers aimed to include every business unit that can directly affect the patient experience, across specialties and departments within a given health system, with the goal of creating an environment a patient can traverse seamlessly. Implementing this module requires an EHR system of record, a system of interaction, and a system of experience. The system of interaction refers to customized online platforms or applications such as those provided by Salesforce and other similar companies. A system of experience involves the patient contact center and may include chatbots and artificial intelligence (AI)-enabled assistants in addition to human representatives.

Myriad online workflows for follow-up care are possible after integrating the EHR and chosen communications platform into the system. The patient workflow can be personalized, convenient, and compassionate while encompassing numerous tasks such as scheduling, appointment and prescription reminders, payment and billing, pre- and postprocedure notifications, satisfaction surveys, wellness reminders, and communication with the contact center. Leveraging EHR data, payer data, and publicly available data—including data on social determinants of health—can support evidence-based analytics and predictive capabilities for understanding patient recovery trajectories. This type of capability could be expanded to include additional metrics relevant to TBI recovery, to enable provision of more customized follow up care.

SOURCES: Presented by David Wright, Disruptive Innovations, May 9, 2023; Customer/Patient Experience (CX/PX) Optimization Module (available at https://www.disruptiveinnovations.net/customer-experience-optimization-module/; accessed September 21, 2023).

Strategies for Improving TBI Follow-Up Care

In response to Oyesanya's question, Baker highlighted the need for multiple strategies, including (1) data collection to establish that interventions are effective, (2) use of data and effective interventions to drive payer recognition, and (3) development of a certification program to enable value-based purchasing. Seabury emphasized that the creation of systems to collect data on a wide patient population would inform which patients require the most intervention after TBI and which interventions are most effective. Such data strengthen the case for payment reimbursement. Whereas

medical claims data are helpful for making such a case for other disease states, TBI claims data are extremely limited and are therefore insufficient for this purpose, he said. Furthermore, important information on TBI outcomes involves people's functioning in areas that are not captured within the health care system, such as employment, education, and quality of life. Given that medical spending does not fully illustrate the ramifications of TBI, the creation of a broader data system that considers patient-reported outcomes and other aspects of recovery could be valuable in generating the evidence for improved TBI care. Wright remarked that segmentation between clinical operations and information technology is common, generating a lack of synergy between practice and data collection, and this is another challenge in creating enhanced data collection and analysis systems for addressing TBI.

Insurance Considerations in TBI Care

Flaura Winston, Children's Hospital of Philadelphia, remarked that when a TBI is caused by a car crash, auto insurance is responsible for associated medical care payments, rather than health insurance. Given that car crashes are the second leading cause of TBI, this feature may diminish the visibility of TBI care within the health insurance industry. This payer aspect differentiates TBI from stroke, in that stroke is only characterized as a medical problem. Seabury acknowledged that auto insurance companies lack incentives to consider the long-term consequences of TBI, as the person injured in a car crash is often not the policy holder. This fuels interest in closing the claim as quickly as possible. He noted that worker's compensation is another type of insurance responsible for TBI claims, and TRACK-TBI data indicate that 20 percent of TBI patients experience long-term employment consequences (Nelson et al., 2019). As a result, longer-term relationships are typically involved with workers compensation claimants. Physician involvement can also help to support a smooth return-to-work process for TBI survivors, including through provision of information and instructions for patients, their families, or employers addressing potential symptoms and accommodations relevant to this transition. Although many health insurance companies do not adopt a long-term perspective in addressing chronic disease, they tend to recognize the possibility of cost offsets, he said. Thus, the health insurance industry is more likely to consider the cost of a potential hospital readmission than are auto or casualty insurers.

Baker summarized that this issue can be framed in terms of the entities that stand to benefit the most from good patient outcomes. Employers may benefit most, but they are not necessarily directly paying for care. The risk of hospital readmission is lower for TBI than for some conditions, and this

lessens the motivation for health insurers to prioritize readmission rates via coverage for excellent care when less expensive options are available. Bundled payments are a method of increasing coverage for follow-up care, but are unlikely to be adequate. Using technology to enable data collection can maximize efficiency of care, he suggested.

Seabury remarked that some TBI outcomes carry expenses beyond acute care that are relevant to health plans. For instance, depression, substance abuse, and other potential associated conditions are costly. However, the medical billing codes for these conditions do not indicate the connection to a person's TBI, and thus additional research is needed to identify such connections. Baker stated that this type of data would likely be effective in driving insurance coverage of improved TBI care. Oyesanya asked whether insurance billing codes currently allow for reimbursement of care management and transition services. Surendra Barshikar, University of Texas at Southwestern Medical Center, commented that charges are possible for tasks that are not face to face, such as extended phone calls or preparing letters, and insurance reimbursement varies for these types of charges.

Communication Approaches to Expanding TBI Follow-Up Care

In response to a question about coordination between physicians, researchers, and other stakeholders regarding clinical informatics, Wright replied that his company has historically collaborated primarily with chief information officers and chief technology officers of health care organizations. However, in recent years they have increased collaboration with chief medical officers and chief health information officers. These leaders are more active in decisions surrounding follow-up care and have greater medical expertise. In some cases, such officers are currently practicing medicine and therefore have a vested interest in ensuring a successful roll out of the health information technology.

Oyesanya asked Baker for strategies on communicating the importance of TBI follow-up care from his experience with the proliferation of comprehensive stroke centers. Baker emphasized the importance of communicating gaps in current TBI care and the effects these gaps have on outcomes. Communication efforts should target payers, such as state Medicaid programs, he suggested. Furthermore, public awareness efforts are needed to establish a shared understanding of the serious nature of TBI and its potential consequences.

Social Determinants of Health Considerations

Wright highlighted progress in leveraging AI-based communication to combat language barriers for individuals. However, such technology is in

the early phases within the health care industry, he said. He is currently working on integrating AI with the EHR to maximize the capabilities of this communication technology. Noting advancements made in recent months in AI algorithms and large language models, he predicted that this area will provide tremendous benefit for people with limited English proficiency within the United States and around the world. Seabury shared that a colleague at USC conducted a large demonstration project via a Centers for Medicare and Medicaid Innovation grant that placed Spanish-speaking pharmacists in clinics with predominantly Hispanic patient populations (USC 2012). The project resulted in better patient adherence to medication regimens and improved outcomes. However, the expense of a full-time pharmacist is substantial, and therefore cost-effective approaches to overcoming language barriers could potentially result in improving outcomes for greater numbers of patients.

Baker maintained that financial cost remains one of the largest barriers to follow-up care. Even smaller copayment amounts can be outside the budgets of individuals with limited income. Moreover, the number of uninsured individuals is likely to increase as some Medicaid expansion programs end. Transportation is another major barrier to accessing care, he noted. Although telehealth and digital health approaches can ameliorate this need, broadband access is not universal. Such considerations need to be integrated into program designs for TBI. For instance, connecting with federally qualified health centers that extend into the community can help to address inequities associated with transportation barriers.

Seabury highlighted the concerns that although pay-for-performance systems can serve as a mechanism for expanding follow-up care services, they may also exacerbate health disparities. Equity considerations are not typically featured in the design of these systems, and therefore better-resourced facilities treating wealthier patients are likely to demonstrate higher levels of performance. It is important to recognize that a system designed in the absence of equity considerations may thereby increase the resource gap between health care settings, he said.

Ramifications of Digital Health

Given the growing market of prescription digital therapeutics, a participant asked about payment considerations for prescription digital health for services such as cognitive behavioral therapy or symptom-tracking apps. Wright responded that such technology is most successfully deployed via mobile apps or other digital mediums connected to workflows within a health care organization's I. He added that direct-to-consumer systems, such as those providing ketamine treatment to the public, are outside of his purview. Seabury noted that although direct-to-consumer platforms

raise numerous concerns, they may increase patient access and they may be particularly effective for health concerns patients are embarrassed to raise with their doctors. New innovations entering the market will compete with existing services for health care spending dollars, he reflected. This competition for resources makes the need for value studies and cost-effectiveness research all the more pressing. Wright provided the example of a company that is currently expanding by approximately 200 percent month over month by prescribing medications for behavioral health or psychiatric conditions that general practitioners are not typically well-versed on. Digital health companies offload this service provision through revenue-sharing agreements with primary care physicians.

Baker highlighted that hybrid models of digital behavioral health care services combine online tools with physician services, and these models have been studied via randomized controlled trials for over a decade. Whereas freestanding online tools may be designed to drive business and generate maximum revenue, hybrid or digitally enabled care models can be designed to achieve the best possible outcome at the lowest cost. Migrating from fee-for-service models to bundled payments and using new types of hybrid models that integrate face-to-face, digital, and telephone communications is one potential avenue to improve outcomes following conditions such as TBI while decreasing costs.

6

Integrating Insights to Catalyze Change

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Key Messages Highlighted by Individual Speakers

- Expansion of the traumatic brain injury evidence base could enhance the development of new treatments and interventions and support efforts to secure funding for care and research needs. (Corrigan, McCrea, Peek-Asa)
- Academic institutions can increase their collaboration with community-based organizations and drive policy change to improve systems of TBI care. (Diaz-Arrastia, McCrea, Turner, Winston, Wolfkiel)
- Demonstration projects are a mechanism for testing and implementing needed changes to TBI care systems in the shorter term, developing a better understanding of how to effectively treat TBI, and creating a value case for investment in TBI care. (Corrigan, Lee, Manley)
- Efforts to expand TBI care need to consider the physiological responses at the intersection of trauma and TBI and the social determinants of health that influence recovery. (McCrea, Peek-Asa)
- The aging process can induce a reemergence of post-TBI effects years after an individual last experienced symptoms. (Corrigan)
- Artificial intelligence is one tool that could potentially be used to improve analyses of brain imaging and increase provider

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capacity, and to help identify patient profiles that warrant higher levels of post-TBI intervention. (Barde, McCrea)

NOTE: This list is the rapporteurs' summary of points made by the individual speakers identified, and the statements have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They are not intended to reflect a consensus among workshop participants.

The final session of the workshop featured a discussion integrating key messages and lessons from the prior sessions into approaches addressing gaps in follow-up care during the first months after a TBI. Michael McCrea, Medical College of Wisconsin, served as moderator and opened the discussion by sharing his view of the importance of the neuro-bio-psycho-socio-ecological model of TBI care featured in the workshop and in the National Academies' recent TBI report (NASEM, 2022). Such a model considers not only the medical nature of a person's brain injury, but also individualized needs and goals, social determinants of health, and the potential effects of factors such as psychological trauma. He also highlighted how the workshop's presentations and discussions reflected an understanding of key components involved in high-quality TBI follow-up systems, encouraging the community working to improve post-TBI care not to ignore or postpone solutions that could address 80 percent of needs while seeking a perfect solution that meets all needs. McCrea then invited all workshop speakers and participants to share their take-away thoughts and key messages from the event.

TBI DATA GAPS

Corinne Peek-Asa, vice chancellor for research, University of California San Diego, emphasized the importance of outcomes data in creating systemic and policy change for TBI care. She noted the need for longitudinal data to measure outcomes as well as data to better quantify TBI burden, incidence, and prevalence. McCrea remarked that data are also critical for developing improved understanding of the effectiveness of treatments, for generating payer support for the value of follow-up care after TBI, and for catalyzing ongoing performance improvement among providers. James Kelly, University of Colorado, agreed and noted that the development and selection of specific outcome metrics for TBI follow-up could be part of the agenda of a future forum meeting.

ACADEMIC AND COMMUNITY PARTNERSHIPS INCHANGE EFFORTS

Flaura Winston, Children's Hospital of Philadelphia, commented that academic institutions can increase their collaboration with community groups serving the TBI population by assisting with grant writing, data collection, and data analysis. Given the potential disconnection between academia and brain injury associations, McCrea echoed the call for greater academic support of community initiatives. Ramon Diaz-Arrastia, University of Pennsylvania, remarked that the Brain Attack Coalition's influence on the creation of a stroke center certification demonstrates how academic groups can take part in motivating policy change and encouraged further action by the TBI community.

April Turner, Alabama Department of Rehabilitation Services, noted that the Alabama TBI system of care uses a taskforce to increase cross-stakeholder collaboration and that similar strategies could be used by others. A quarterly newsletter informs taskforce members of current activities and provides transparency; federal workgroups create opportunities for state partners to collaborate, as well. Rebeccah Wolfkiel, National Association of State Head Injury Administrators, shared that her organization is available to help facilitate connections with state and local programs and the organization's website can serve as a resource that lists brain injury community programs.

APPROACHES TO BUILDING COMPREHENSIVE TBI CARE

Noting the broad scope of improvements needed in post-TBI care raised during this workshop, David Brody, professor of neurology and chief science officer/chief innovation officer at the Center for Neuroscience and Regenerative Medicine, Uniformed Services University, asked how best to organize and prioritize initiatives. McCrea replied that the forum's recently established Action Collaborative on TBI Care can serve as one vehicle to help advance these issues and that the Action Collaborative has prioritized several initial action areas through working groups focused on specific needs within the broader landscape. Geoffrey Manley, University of California San Francisco, added that the Action Collaborative adopted its initial focus on adults because 80 percent of TBI patients are aged 18 years or older, and thus improvements in postacute TBI care for this segment of the patient community could have a broad impact. In addition to the work of the Action Collaborative's Clinical Practice Guidelines group, which is working to improve quality of life by identifying and disseminating guidance to manage the most common symptoms experienced after a TBI, he highlighted that the Action Collaborative seeks to foster the creation of

pilot post-TBI care sites across the country. Research, patient, and family/caregiver input is critical to inform the implementation and evolution of such pilot programs, Manley emphasized, and such pilots can develop an improved evidence base from which to scale efforts and broaden the populations served. The process of identifying care systems and settings that could form a pilot initiative and securing matching funds is already underway, Manley added.

Kathy Lee, Department of Defense (DoD), echoed the scope of the challenges in TBI follow-up care and the fact that attempting to address all potential changes simultaneously would be overwhelming. She emphasized the value and feasibility of developing a pilot demonstration project for adult, postacute TBI that could serve as a proof of concept, and that timed start and end points and specific goals can provide structure while the iterative nature of a demonstration project facilitates ongoing learning. Lee pointed to a proof-of-concept pilot program designed as part of the DoD's Warfighter Brain Health Initiative as an example of the type of effort that could be undertaken,[1] noting that the DoD pilot features six specific tasks limited to a 3-year timeline. This program aims to clearly define the scope of the problem and generate data illustrating how brain health is a public health issue, she said, thereby demonstrating the need for such brain health programs to a broader set of stakeholders. Lee emphasized that such demonstration projects can be implemented in the shorter term and further refined and expanded over time, enabling progress on actionable tasks. Complementary policy change can be pursued by leveraging national channels such as the Congressional Brain Injury Task Force and the Brain Injury Association of America, she concluded.

John Corrigan, The Ohio State University, commented on the value of including a Medicaid managed care organization (MCO) in a future pilot for improved post-TBI care, given that one-fifth of TBI clinics in Ohio are funded by Medicaid MCOs. Furthermore, Medicaid diagnostic code data could be used to identify outcome trajectories of TBI patients who initially sought medical treatment but did not receive ongoing management. Such data could also inform analysis of the return on investment from changes to TBI follow-up care.

A participant asked about currently available evidence that indicates the effectiveness of interventions that are not yet widely implemented, encouraging providers to begin implementing such interventions in their practices and clinics as an early step toward broader change. Frederick Korley, University of Michigan, noted the role for pragmatic clinical trials

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[1] More information about the Warfighter Brain Health Initiative is available at https://media.defense.gov/2022/Aug/24/2003063181/-1/-1/0/DOD-WARFIGHTER-BRAIN-HEALTH-INITIATIVE-STRATEGY-AND-ACTION-PLAN.PDF (accessed July 13, 2023).

as a useful mechanism for gathering evidence on the effectiveness or lack of effectives of interventions addressing TBI and helping to advance practice standards.

Carl Long, chief executive officer, NeuroTrauma Sciences LLC, underscored the role of pharmaceutical companies and investment funds in medical innovation. He noted the potential value of inviting representatives from these groups to present to the forum on funding priorities and value propositions. Such a session could illustrate areas of overlapping interests between funders and investors and the TBI community and provide further insights on making effective value cases. McCrea remarked that often these stakeholders also use epidemiologists, data scientists, neuroscientists, and other experts on subjects relevant to TBI, adding to the value of engaging with them during future events.

TRAUMA AND EQUITY CONSIDERATIONS

Peek-Asa emphasized the importance of considering issues related to equity and trauma while aiming to enhance care provision after TBI. Head trauma often results from traumatic events such as active combat, violence, or car crashes involving deaths. Psychological trauma is linked to a cascade of biochemical sequelae that increases the risk of additional TBIs. Moreover, TBI causes biomechanical and biochemical responses. The effects of these responses and of social determinants of health influence recovery, she said, thus TBI systems of care need to better integrate this understanding into practice. McCrea agreed that both the literature and the experiences of providers, patients, and families demonstrate that a TBI care system cannot succeed without taking trauma and social determinants of health into account.

TBI DISCHARGE INSTRUCTIONS

A participant emphasized the pressing need for codified TBI discharge instructions that feel personalized and provide patients with a sense of agency and a hopeful path forward during their recovery. McCrea remarked on the variability among discharge instructions currently used by hospitals—even within the same health care system—and the lack of consistency in providing them to patients. Matthew Breiding, Centers for Disease Control and Prevention, commented that creating the content and aesthetic of such instructions is far easier than implementing automatic dissemination at discharge. He noted that many settings distribute instructions with low resolution and poor quality, indicating that photocopies are made from previous photocopies. Shifting from these old-fashioned methods to a universal system would be valuable, but it will be a substantial challenge. McCrea also

raised the issue of timing when providing post-TBI instructions to patients and families, and the need to consider the patient's state of mind after injury. This speaks to the need for the Action Collaborative's groups to coordinate with CDC and other experts in developing further high-quality, standardized resources and encouraging adoption of them, he said.

REHABILITATION CONSIDERATIONS

A participant commented on the challenge of inadequate insurance coverage for rehabilitation services after TBI, since some people may require years of services. Many TBI survivors also have trajectories that involve mental health issues that are not well identified or treated with current follow-up care. McCrea noted that once a patient is discharged from inpatient rehabilitation, insurance benefits generally limit coverage for both the quantity of visits and the time frame in which visits occur. Corrigan commented that some TBI patients recover and do well for a number of years, but later experience an interaction of aging and residual TBI effects that contribute to health failures at earlier ages than their peers. This interaction can create service needs years after the termination of initial post-TBI interventions. The longer-term consequences of TBI, the intersection of a prior TBI with subsequent aging, and the challenges of providing and covering the longer-term, multidisciplinary rehabilitation interventions needed by some TBI patients represents another area to consider for future forum meetings, he concluded.

ARTIFICIAL INTELLIGENCE CONSIDERATIONS

A participant spoke of the advantages and limitations of artificial intelligence (AI) as a potential resource for the TBI field, given the current lack of health system capacity to meet TBI needs and the large numbers of people who experience a TBI each year. For example, the use of algorithms in three- and four-dimensional cardiac imaging is reducing the time cardiology staff must dedicate to assessment, he said. He remarked that a similar approach might perhaps be applied to brain imaging. For instance, brain imaging may indicate that a TBI is isolated to the speech center in the left hemisphere of a patient's brain, reducing the need for a full battery of diagnostic tests. AI informatics could potentially be used to target treatments to certain sets of vital signs or imaging. Similar to Poison Control, which identifies treatments for symptoms after a toxic chemical exposure, an AI-enabled resource could help direct physicians to those TBI interventions most likely to lead to a better outcome, based on the specific patient information.

Furthermore, he noted that car companies are developing technology to capture details of car crash events, additional data that could be trans-

mitted to an Emergency Medical Services (EMS) dispatch center and into an electronic patient reporting system to inform subsequent patient assessment. Using AI with imaging technology and other patient information to assess the characteristics of a TBI and assist in targeting care could be a strategy to reduce cost and time demands on providers, reduce variation, and increase reliability and capacity, he suggested. The intersection of data about a specific patient and the thousands of data points in existing TBI registries could also yield additional understanding that translates into beneficial interventions for TBI, but these data are too numerous for any individual physician or neurosurgeon to analyze.

Adam Barde, Slalom Consulting, noted that his company is currently developing a platform that uses a simple algorithm to determine whether a symptom reaches a certain threshold to flag for providers. However, future versions may use AI in other ways and feature learning aspects. Algorithms developed to analyze imaging in the diagnosis of melanoma, breast cancer, and cervical cancer, for example, have matched or surpassed human accuracy levels, indicating potential for future TBI uses, he noted. David Wright, Disruptive Innovations, remarked that technology tools need to be used in combination with human expertise, rather than seen as replacements. These tools can be particularly useful in the knowledge management arena, which features fewer patient-facing implications and less risk from an administrative burden standpoint.

McCrea described AI applications in TBI as "the great unknown," stating that the potential prognostic usefulness of AI in TBI models should not be dismissed and requires further investigation. For example, AI-enabled analysis drawing on large datasets could suggest which patients are predicted to have good outcomes or poor outcomes, assisting providers to identify interventions for the latter group that facilitate their recovery. Innovations augment, rather than replace, a clinician's expertise, he emphasized, and hold potential to improve diagnostic accuracy, prognostic modeling, and—ultimately—contribute to better outcomes for patients.

WORKSHOP WRAP-UP

McCrea closed out the workshop, thanking the workshop planning committee, speakers and moderators, and participants for the active and informative discussions over the course of the day. The workshop sessions highlighted patient, family, and provider needs associated with TBI follow-up care, as well as providing examples of models and strategies that can better support high-quality follow-up care and care continuity after injury, he reflected, concluding that such discussions and others among the varied organizations and communities active in TBI care and research will continue to inform the forum and its future work.

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B

Workshop Statement of Task and Agenda

WORKSHOP STATEMENT OF TASK

A planning committee of the National Academies of Sciences, Engineering, and Medicine will organize and conduct a 1- to 1.5-day public workshop that brings together experts and key stakeholders to explore needs, practices, and models for postacute follow-up care and symptom management in civilian adults discharged from emergency departments after a traumatic brain injury (TBI). The public workshop will feature invited presentations and discussions, which may be designed to:

- Center and integrate patient and community perspectives and priorities on postacute TBI care following emergency department discharge;
- Highlight opportunities for improved TBI outpatient symptom monitoring, management, and recovery;
- Consider potential lessons to be learned from models and practices of at-home management for other medical conditions; and
- Explore the feasibility and health economics associated with implementing improvements to TBI postacute follow-up care after emergency department discharge.

With the assistance of staff, the planning committee will develop the agenda for the workshop, select and invite speakers and discussants, and moderate the discussions. A proceedings of the presentations and discussions at the workshop will be prepared by a designated *rapporteur* in accordance with institutional guidelines.

WORKSHOP AGENDA

Tuesday, May 9, 2023

9:00   **Session 1: Introduction to Why TBI Follow-Up Care Is a Significant Gap**

Welcome: DONALD BERWICK, Institute for Healthcare Improvement and *Chair, Forum on Traumatic Brain Injury*

Workshop Overview: MICHAEL MCCREA, Medical College of Wisconsin and *Chair, Workshop Planning Committee*

9:20   **Session 2: Introduction to the Forum's Action Collaborative on TBI Care**
Introduction to the focus and goals of the newly formed Action Collaborative and its workstreams, followed by discussion.

Introduction: GEOFFREY MANLEY, University of California, San Francisco

Reflections from Action Collaborat ive Working Groups
1. Clinical Practice Guidelines—KATHY LEE, Department of Defense, and NOAH SILVERBERG, University of British Columbia (virtual)
2. TBI Education and Discharge Instructions—MATTHEW BREIDING, Centers for Disease Control and Prevention, and ODETTE HARRIS, Stanford University
3. Follow-Up Care After TBI—FLORA HAMMOND, Indiana University School of Medicine, and MICHAEL MCCREA, Medical College of Wisconsin
4. Designing a Learning Health Care System for TBI Care—GLEN JACQUES and ADAM BARDE, Slalom Consulting
5. Patient Perspectives—SCOTT HAMILTON, TBI survivor and patient advocate

Moderated Discussion
AMY MARKOWITZ, University of California, San Francisco, *Moderator*
GEOFFREY MANLEY, University of California, San Francisco

> KATHY LEE, Department of Defense, and NOAH
> SILVERBURG, University of British Columbia
> (virtual)
> MATTHEW BREIDING, Centers for Disease Control
> and Prevention, and ODETTE HARRIS, Stanford
> University School of Medicine
> FLORA HAMMOND, Indiana University School of
> Medicine, and MICHAEL MCCREA, Medical College
> of Wisconsin
> ADAM BARDE and GLEN JACQUES, Slalom Consulting
> SCOTT HAMILTON, TBI survivor and patient advocate

10:40   Break

11:00   **Session 3: Necessary and Vital Components for Achieving a
System of Follow-Up Care for Mild TBI**
Identification of essential elements for TBI follow-up
and transitional care, drawing on selected models being
developed and implemented in different settings.

> Session Overview: JAVIER CÁRDENAS, Rockefeller
> Neuroscience Institute at West Virginia University,
> *Moderator*

> Big Picture: Key Components of Care Transitions: KAREN
> HIRSCHMAN, University of Pennsylvania School of
> Nursing

> Essential Elements for Discharge Planning and Transitional
> Care: TOLU OYESANYA, Duke University School of
> Nursing

> Examples of Follow-Up Care Models after Mild TBI:
> TEENA SHETTY, Hospital for Special Surgery, New York
> SURENDRA BARSHIKAR, University of Texas Southwest
> Medical Center
> MICHAEL MCCREA, Medical College of Wisconsin

12:00   Lunch

12:50   **Necessary and Vital Components for Achieving a System of Follow-Up Care in Mild TBI,** *Continued*

Moderated Discussion
    JAVIER CÁRDENAS, Rockefeller Neuroscience Institute
      at West Virginia University, *Moderator*
    KAREN HIRSCHMAN, University of Pennsylvania
      School of Nursing
    TOLU OYESANYA, Duke University School of Nursing
    TEENA SHETTY, Hospital for Special Surgery, New York
    SURENDRA BARSHIKAR, University of Texas
      Southwest Medical Center
    MICHAEL MCCREA, Medical College of Wisconsin

1:30   **Session 4: Key Considerations for Achieving Effective Follow-Up Care Systems During the Initial Year Postinjury**
Factors outside the clinic itself that need to be addressed when designing and implementing systems of follow-up care for TBI at the milder end of the severity spectrum. Panelists will discuss such issues as reimbursement, social determinants of health, and access to care and community services.

Session Overview: JOHN CORRIGAN, The Ohio State
    University, *Moderator*

Addressing Social Determinants of Health Affecting TBI
    Recovery: MONIQUE PAPPADIS, University of Texas
    Medical Branch

Fundamentals of Trauma-Informed Care for Vulnerable
    Populations: JULIANNA NEMETH, The Ohio State
    University

Designing and Accessing Appropriate Community Services:
    REBECCAH WOLFKIEL, National Association of State
    Head Injury Administrators, and APRIL TURNER,
    Alabama Department of Rehabilitative Services

Moderated Discussion
    JOHN CORRIGAN, The Ohio State University, *Moderator*
    REBECCAH WOLFKIEL, National Association of State
    Head Injury Administrators

APRIL TURNER, Alabama Department of Rehabilitative
   Services
JULIANNA NEMETH, The Ohio State University
MONIQUE PAPPADIS, University of Texas Medical
   Branch

2:45   Break

3:10   **Session 5: Enabling Improvements to Systems of Follow-Up
                Care—Perspectives on the Roles of Certification, Incentives,
                and Information Management Systems**
                Strategies to support the ability of follow-up care systems to
                adjust in size or scope, to be applied in additional settings,
                and to be sustainable over time.

                Session Overview: TOLU OYESANYA, Duke University
                   School of Nursing, Moderator

                Establishing Standards of Care: Lessons from the Stroke
                   Center Program: DAVID BAKER, The Joint Commission
                   (virtual)

                The Roles of Financial Incentives: SETH SEABURY,
                   University of Southern California

                Digital Business and Technology to Advance Health Systems:
                   DAVID WRIGHT, Disruptive Innovations

                Moderated Discussion
                   TOLU OYESANYA, Duke University School of Nursing,
                      Moderator
                   DAVID BAKER, The Joint Commission (virtual)
                   SETH SEABURY, University of Southern California
                   DAVID WRIGHT, Disruptive Innovations

4:20   **Session 6: Integrating Insights to Catalyze Change**
                Discussion among workshop participants drawing out key
                messages and lessons from the workshop.
                MICHAEL MCCREA, Medical College of Wisconsin,
                   Workshop Chair

4:50   **Concluding Remarks**
              MICHAEL MCCREA, Medical College of Wisconsin,
                 Workshop Chair

5:00   **Adjourn Workshop**

C

Speaker and Moderator Biographies

David W. Baker, M.D., M.P.H., FACP, is the executive vice president for Health Care Quality Evaluation at The Joint Commission in Oakbrook Terrace, Illinois. He leads the Department of Standards and Survey Methods, the Department of Quality Measurement, and the Department of Research. Before assuming his current position, Dr. Baker was the Michael A. Gertz Professor of Medicine at the Feinberg School of Medicine at Northwestern University and deputy director of the Institute for Public Health and Medicine. He served from 2002 to 2015 as chief of the Division of General Internal Medicine and Geriatrics. In this capacity, he oversaw the General Internal Medicine ambulatory clinic, residents' continuity of care clinics, and the division's research programs. Dr. Baker also maintained his own very active research portfolio. He is nationally and internationally recognized for his work examining health literacy and the consequences of inadequate health literacy, racial and ethnic disparities, the effect of language barriers on health care, and differences in health outcomes for the uninsured. Dr. Baker has also conducted extensive research in quality of care, focusing on the use of electronic health records for quality measurement and quality improvement. He has published over 250 original research articles and book chapters and has won numerous awards, including the 2013 American College of Physicians' Alvan R. Feinstein Memorial Award for research in clinical epidemiology. Dr. Baker is also Editor-in-Chief for the *Joint Commission Journal on Quality and Patient Safety*.

Adam Barde, M.H.A, M.S.G, is a senior principal at Slalom on the health care and life sciences team, working in such areas as health care innova-

tion and transformation, patient and provider experience, and clinical operations and management. Mr. Barde has focused on transforming the patient and provider experience for over 25 years, with experience in program assessment, development, and implementation; disease management; market research; and network development. He was previously Senior Director, Health Transformation, at Blue Shield of California. He received a Master of Health Administration and an M.S. in Gerontology from the University of Southern California.

Surendra Barshikar, M.D., M.B.A., is associate professor and vice chair of clinical operations for the Department of Physical Medicine and Rehabilitation (PM&R) at UT Southwestern Medical Center. He specializes in concussion and traumatic brain injury, neurorehabilitation, spasticity management, and rehabilitation and management of long COVID. He joined the UT Southwestern faculty in 2016 and is double-board-certified in physical medicine and rehabilitation and brain injury medicine by the American Board of Physical Medicine and Rehabilitation. In addition to his other roles, Dr. Barshikar is the Medical Director of the UT Southwestern PM&R Ambulatory Clinics and the Parkland PM&R Outpatient Clinics, as well as the Medical Director of the multidisciplinary concussion program and the COVID Recovery program. He collaborates with other departments, including Neurology, Neurosurgery, and Neuroradiology, for various research studies on long COVID and neurorehabilitation. Dr. Barshikar has delivered many presentations, contributed to the books T*extbook of Traumatic Brain Injury* and *Practical Guide for Botulinum Toxin Injections*, and published numerous academic articles, abstracts, reviews, and case reports related to his areas of expertise. He is a member of the International Society of Physical and Rehabilitation Medicine, the American Academy of Physical Medicine and Rehabilitation, the Association of Academic Physiatrists, the Texas Medical Association, the Dallas County Medical Society, the Texas Medical Board, and the Maharashtra Medical Council.

Donald M. Berwick, M.D., M.P.P., FRCP, is president emeritus and senior fellow at the Institute for Healthcare Improvement and former administrator of the Centers for Medicare & Medicaid Services. A pediatrician by background, Dr. Berwick has served on the faculty of the Harvard Medical School and Harvard School of Public Health, and on the staffs of Boston's Children's Hospital Medical Center, Massachusetts General Hospital, and the Brigham and Women's Hospital. He has also served as vice chair of the U.S. Preventive Services Task Force, the first "independent member" of the American Hospital Association Board of Trustees, and chair of the National Advisory Council of the Agency for Healthcare Research and Quality. He served two terms on the Institute of Medicine's (IOM's) Gov-

erning Council, was a member of IOM's Global Health Board, and served on President Clinton's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry. Recognized as a leading authority on health care quality and improvement, Dr. Berwick has received numerous awards for his contributions. In 2005, he was appointed "Honorary Knight Commander of the British Empire" by Her Majesty, Queen Elizabeth II, in recognition of his work with the British National Health Service. Dr. Berwick is the author or coauthor of over 160 scientific articles and six books. He currently serves as lecturer in the Department of Health Care Policy at Harvard Medical School.

Matthew Breiding, Ph.D., currently serves as acting deputy associate director of science in the Division of Violence Prevention at the Centers for Disease Control & Prevention (CDC). He was previously serving as team lead of the Traumatic Brain Injury Team in the Division of Injury Prevention at CDC's Injury Center. His work at CDC has been focused on the surveillance of traumatic brain injury, intimate partner violence, sexual violence, and child abuse—both national and international. He began his career at CDC as an Epidemic Intelligence Service (EIS) officer, assigned to CDC's Division of Violence Prevention. Upon completion of his 2-year EIS fellowship, he remained with the Division of Violence Prevention, serving as a behavioral scientist. Dr. Breiding received a Bachelor of Science degree in Industrial and Systems Engineering from Ohio State University and masters and doctoral degrees in Counseling Psychology from the University of Notre Dame. He completed a postdoctoral clinical residency at the Washington University in the St. Louis Student Health and Counseling Center. He is a licensed psychologist in the state of Missouri. He has coauthored more than 70 peer-reviewed publications, government reports, and book chapters, and has received a number of awards for his work in public health.

Javier Cárdenas, M.D., is a professor and chief of the Division of Sports Neurology at the Rockefeller Neuroscience Institute, West Virginia University. He was formerly director of the Barrow Concussion and Brain Injury Center. He is board certified in neurology by the American Board of Psychiatry and Neurology. Dr. Cárdenas' expertise involves concussion, postconcussion syndrome, spinal trauma, and traumatic brain injury. He is a member of the American Academy of Neurology; the National Football League Head, Neck, and Spine Committee; and the Arizona Governor's Advisory Council on Spinal and Head Injuries. Dr. Cárdenas received his medical degree from the University of Arizona College of Medicine. He completed a residency in pediatrics at St. Joseph's Hospital and Medical Center and trained in child neurology at Barrow Neurological Institute. Dr. Cárdenas founded the Barrow Concussion and Brain Injury Center, which

is recognized as one of the most comprehensive concussion prevention, treatment, and education programs in the United States. He also created Barrow Brainbook as part of a program that Arizona high school students must complete to participate in school sports. It is the first mandated online concussion education and testing tool for student athletes in the country.

John Corrigan, Ph.D., is an academy professor in the Department of Physical Medicine and Rehabilitation at The Ohio State University. He serves as the director of the Ohio Valley Center for Brain Injury Prevention and Rehabilitation. He also directs the Ohio Brain Injury Program, the lead agency in the State of Ohio for policy and planning related to living with brain injury. Dr. Corrigan has received local and national awards for his service and research in the field of brain injury rehabilitation, including the Gold Key Award from the American Congress of Rehabilitation Medicine, the Brain Injury Association of America's William Fields Caveness Award, and the 2007 Robert L. Moody Prize. He is a Fellow of the American Association for the Advancement of Science, the American Congress of Rehabilitation Medicine, and the American Psychological Association. Dr. Corrigan is the principal investigator and coprincipal investigator for the Ohio Regional Traumatic Brain Injury Model System—a multicenter, longitudinal research program funded by the National Institute on Disability Independent Living and Rehabilitation Research. For 10 years he chaired the Executive Committee of the TBI Model Systems Project Directors. He is a member of the Board of Directors of the Brain Injury Association of America, and previously served on the Advisory Committee to the National Center on Injury Prevention and Control at the Centers for Disease Control and Prevention, the Defense Health Board Neurological/Behavioral Health Subcommittee, and the Board of Directors of the Commission on Accreditation of Rehabilitation Facilities (CARF).

Scott W. Hamilton is a social entrepreneur, having created four start-ups with a strong track record of results. He is now focused on using all that has been learned about the brain in neuroscience to improve children's learning. Mr. Hamilton designed and for 5 years led the effort to grow the Knowledge Is Power Program (KIPP) from two schools in 2000 to 280 of the best known and celebrated inner-city public schools in America today with 175,000 students and alumni. He guided the investment of over $100 million from the Fishers, the founders of Gap, Inc., into KIPP and into the quadrupling of the Teach for America teaching corps, the creation of the Charter School Growth Fund, and more. He has held posts in the White House, with the U.S. Secretary of Education, and served as Massachusetts' Associate Commissioner of Education. He earned his degree in Ancient Greek at the University of Pennsylvania.

Flora Hammond, M.D., is a board-certified physical medicine and rehabilitation physician and physiatrist, and is active as a clinician, researcher, and administrator. She completed her medical degree at Tulane University School of Medicine, her Physical Medicine and Rehabilitation residency at Baylor College of Medicine, and her Brain Injury Medicine fellowship at the Rehabilitation Institute of Michigan. She is professor and chair of physical medicine and rehabilitation at Indiana University School of Medicine. She is also the chief of medical affairs and brain injury and the comedical director at the Rehabilitation Hospital of Indiana. She is the project director of the Indiana Traumatic Brain Injury Model System, and chair of the TBI Model Systems Program Executive Committee. Dr. Hammond also chairs the Chronic Brian Injury Special Interest Group of the TBI Model Systems, cochairs the American Congress of Rehabilitation Medicine Chronic Brain Injury Task Force, and chairs the Tri-Model Systems Chronic Injury Special Interest Group. She has helped pioneer the transition of brain injury care from brief attention early on to care spanning one's lifetime to optimize the outcomes possible after brain injury.

Odette Harris, M.D., M.P.H., is the Paralyzed Veterans of America Professor of Spinal Cord Injury Medicine, a professor of neurosurgery and the vice chair for diversity and director of Brain Injury at Stanford University School of Medicine. She is also the deputy chief of staff, Rehabilitation at the Veterans Affairs Palo Alto Health Care System, overseeing the TBI/Polytrauma System of Care, Spinal Cord Injury, Blind Rehabilitation Services, Recreational Therapy and Physical Medicine & Rehabilitation. Dr. Harris graduated from Dartmouth College and received her M.D. from Stanford University School of Medicine. She did her internship and residency at Stanford and earned a Master of Public Health, Epidemiology, from the University of California, Berkeley. Dr. Harris has authored numerous articles/books and is a member of several Editorial Boards and National Committees including as the Associate Editor for *Neurosurgery* and as an appointed Member, National Football League (NFL) Head, Neck and Spine Committee. She also serves on several Boards including the Defense Health Board's (DHB) Trauma and Injury Subcommittee and a Trustee of Dartmouth College. She has won numerous awards: Appointed a Fellow of the Aspen Global Leadership Network in 2018; Recognized in 2019 by *Forbes* and *Ebony Magazine* Power 100 List Award as one of 100 most influential African Americans, and received the National Medical Fellowships Award for Excellence in Academic Medicine. In 2021 she received the Stanford RISE Award. In 2022, Dr. Harris was recognized by Stanford University as one of Stanford's 13 women's history makers. Dr. Harris' Endowed Professorship further distinguishes her as the first woman in Neurosurgery at Stanford to receive this honor.

Karen Hirschman, Ph.D., M.S.W., is the NewCourtland Term Chair in Health Transitions Research and a research professor in the University of Pennsylvania's School of Nursing. As a nationally recognized researcher, Dr. Hirschman's career has focused on improving health care transitions for older adults and their family caregivers, with a specific emphasis on those living with cognitive impairment. She is a member of the Transitional Care Model team, led by Dr. Mary Naylor. This rigorously tested advanced practice registered nurse-led model targets high-risk hospitalized older adults and focuses on transitional care to improve outcomes for older adults and their family caregivers. The team studies both replication and adaptation of the model into health care settings and fidelity to implementation of the model's components. Dr. Hirschman is a Fellow of the Gerontological Society of America.

Glen Jacques is a managing director for Slalom's Northern California market and leads the Healthcare and Life Sciences industry vertical. Slalom is a global business and technology consulting company with over 14,000 employees across 43 markets. Slalom's purpose is to help people and organizations dream bigger, move faster, and build better tomorrows for all. Mr. Jacques and his Slalom colleagues partner with clients to improve the health of people around the world. He has 23 years of experience in strategy and technology consulting for Fortune 500 companies and manages the relationship between Slalom and UCSF, as well as many other local industry clients. He has vast expertise in developing impactful client relationships, building high performance teams, and leading complex enterprise-wide technology and strategy programs.

Kathy Lee, M.S., CRNP, ANP-BC, CNRN, currently serves as the director of Casualty Management Policy & Programs and is the lead for the U.S. Department of Defense Warfighter Brain Health program supporting the Deputy Assistant Secretary of Defense for Health Readiness Policy and Oversight. She brings considerable clinical, educational, and research experience in the field of neuroscience and neurotrauma to include more than 200 regional, national, and international presentations and more than 30 peer-reviewed publications. Ms. Lee has served in a variety of leadership, advisory and operational roles in the U.S. Department of the Army and U.S. Department of Defense for over 15 years, including the Assistant Chief of the Defense and Veterans Brain Injury Center (DVBIC), Deputy Director for the Defense Centers of Excellence for Psychological Health and Traumatic Brain Injury, Deputy Director for the Clinical and Educational Affairs Office for DVBIC, and the manager of the Office of Clinical Standards at DVBIC. Prior to working in Washington, D.C., Ms. Lee worked in two academic/Level I trauma centers as a nurse practitioner/clinical care coordinator at

the University of Louisville Hospital; and clinical research coordinator in the Division of Neurosurgery at the Medical College of Virginia Hospitals/Virginia Commonwealth University. Ms. Lee holds both Bachelor's and Master's degrees in nursing from Virginia Commonwealth University, as well as a Bachelor of Science in family and child development from Virginia Tech University. She has earned the certification of Adult Nurse Practitioner (ANP) through the American Nurses Credentialing Center.

Geoffrey Manley, M.D., Ph.D., is the chief of neurosurgery at the Zuckerberg San Francisco General Hospital (ZSFG) and is the professor and vice chairman of neurosurgery at the University of California, San Francisco. Dr. Manley is an internationally recognized expert in neurotrauma. In addition to a robust clinical practice at ZSFG, San Francisco, and the Greater Bay Area's Level 1 trauma center, he coordinates and leads national and international clinical research efforts in the study of the short- and long-term effects of TBI. With a nationwide team of TBI experts, he has recently launched the TRACK-TBI NETWORK, an innovative, precision-medicine driven consortium that will test Phase 2 drugs for TBI. The TRACK-TBI studies have created a modern precision medicine information commons for TBI that integrates clinical, imaging, proteomic, genomic, and outcome biomarkers to drive the development of a new TBI disease classification system, which could revolutionize diagnosis, direct patient-specific treatment, and improve outcomes.

Amy J. Markowitz, J.D., is the scientific writing specialist and editorial consultant for the University of California, San Francisco's Clinical and Translational Research Career Development Program, and program manager for the Traumatic Brain Injury Endpoints Development Initiative at San Francisco General Hospital. She is a freelance editor, scientific writing mentor and instructor, and curriculum development consultant, with a special focus on medicine and health policy, and serves as the project editor for the UCSF Health Workforce on Long-Term Care Research Center. Ms. Markowitz was a cocreator and founding managing editor of JAMA's "Care of the Aging Patient" section and served in the same capacity for JAMA's "Perspectives on Care at the Close of Life" section, and the Annals of Internal Medicine's "Quality Grand Rounds" series. In addition to her work at UCSF, she has served as writer and editor for such diverse clients as Google, the California HealthCare Foundation, and amFAR TREAT, Asia's HIV network based in Bangkok, Thailand. She has developed an interest and expertise in assisting writers and researchers writing for English-language journals for whom English is not a first language, as well as for investigators with learning differences.

Michael McCrea, M.D., is a board-certified clinical neuropsychologist. He is currently the Shekar N. Kurpad, M.D., Ph.D., Chair in neurosurgery; professor of neurosurgery and neurology; vice chair of research; codirector of the Center for Neurotrauma Research; and director of Brain Injury Research at the Medical College of Wisconsin in Milwaukee, Wisconsin. Dr. McCrea earned his doctoral degree from the University of Wisconsin-Milwaukee, then completed his internship training in neuropsychology at Vanderbilt University School of Medicine, followed by a postdoctoral fellowship at Northwestern University Medical School. He is a past President of the American Academy of Clinical Neuropsychology (AACN). Dr. McCrea has been an active researcher in the neurosciences, with numerous scientific publications, book chapters, and national and international lectures on the topic of traumatic brain injury. He authored the text *Mild Traumatic Brain Injury and Postconcussion Syndrome: The New Evidence Base for Diagnosis and Treatment* published by Oxford University Press. He is a member of the United States Department of Defense Health Board External Advisory Committee on Traumatic Brain Injury, where he advises the Office of the Secretary of Defense on management and research of military-related traumatic brain injury.

Julianna Nemeth, Ph.D., M.A., is an intervention scientist dedicated to conducting the scientific work needed to improve health and reduce disparities for those impacted by violence in the context of trauma—most notably women and children exposed to domestic violence and homelessness. Dr. Nemeth's work focuses on building and optimizing behavioral interventions for these populations recognizing the chaotic circumstances in which they live and are trying to recover, heal, and make behavioral change. Informed by nearly 2 decades of community work in violence prevention and crisis response, and trained as a feminist theorist, she also brings gender, culture, justice, and community practice lenses to the study of health behavior and the promotion of health equity. Dr. Nemeth is the cofounder of the Ohio Alliance to End Sexual Violence, a 501(c)3 organization recognized by the Centers for Disease Control and Prevention and the Office on Violence Against Women as Ohio's coalition addressing sexual violence response and its prevention. In addition, she serves as an evaluator on an Office of Victims of Crime funded demonstration grant (2016–2019) awarded to the Ohio Domestic Violence Network; this work focuses on the creation, implementation, and evaluation of the C.A.R.E. model, designed to increase advocacy organizations' capacity to better meet the complex and often interconnected health concerns of domestic violence survivors—including brain injury, mental health, trauma, and substance use.

Tolu Oyesanya, Ph.D., R.N., joined Duke University School of Nursing (DUSON) in 2018, and is a member of the Healthcare in Adult Populations Division. Dr. Oyesanya is an associate professor at DUSON and is also the associate program director for the Duke National Clinicians Scholars Program (NCSP). Dr. Oyesanya's research program focuses on treating patients with traumatic brain injury (TBI) in acute and postacute treatment settings and providing support to their family caregivers. Her current research focuses on transitional care needs of patients with TBI, with an emphasis on improving postdischarge, and self- and family-management of care. Her long-term research goals are to: (1) improve self- and family-management of care for persons with TBI and their family caregivers, and (2) decrease readmissions for persons with TBI. Dr. Oyesanya earned her B.S.N., M.S.N., and Ph.D. in Nursing from University of Wisconsin-Madison. She completed a postdoctoral fellowship in Brain Injury Research at Shepherd Center in Atlanta, Georgia. Her research has been supported by federally and internally funded awards. Dr. Oyesanya is actively involved in several professional organizations, including serving as Chair of the Mentoring Task Force of the American Congress of Rehabilitation Medicine and as a member of the Association of Rehabilitation Nurses and the International Brain Injury Association.

Monique R. Pappadis, M.Ed., Ph.D., is a tenured associate professor in the Department of Population Health and Health Disparities at the University of Texas Medical Branch (UTMB) at Galveston. She is a fellow of the Sealy Center on Aging, and currently the Diversity, Equity, Inclusion and Accessibility (DEIA) Lead for the CTSA Program Steering Committee Task Force/Institute for Translational Sciences. Dr. Pappadis is also an investigator and the director of Dissemination and Cultural Humility at TIRR Memorial Hermann's Brain Injury Research Center in Houston, Texas. Her research aims to improve rehabilitation outcomes and decrease ethnic minority health disparities, particularly among persons with traumatic brain injury (TBI) or stroke, as well as improve care transitions and continuity of care following acute and postacute care. Her recent work aims to improve screening for elder mistreatment with emphasis on vulnerable, older adults with mild cognitive impairment or Alzheimer's disease and related dementias, as well as the intersection between elder mistreatment and TBI. She has a continued interest in minority, aging, and gender/sex disparities in rehabilitation; health literacy of patients and caregivers; and psychosocial adjustment to disability. She is a member of the Academy of Certified Brain Injury Specialists' (ACBIS) Board of Governors for the Brain Injury Association of American and member of the Pink Concussions Professional Advisory Board. Dr. Pappadis was recently named a Fellow of the American Congress of Rehabilitation Medicine (ACRM) for her outstanding record of

professional service to ACRM and for the nationally significant contributions she has made to the field of medical rehabilitation.

Seth Seabury, Ph.D., is director of the Keck-Schaeffer Initiative for Population Health Policy at the USC Schaeffer Center and associate professor in the USC School of Pharmacy in the Department of Pharmaceutical and Health Economics. He is also the director of graduate studies for the Pharmaceutical Economics and Policy Program in the USC School of Pharmacy. His work examines the impact of legal and regulatory policy on health care delivery and patient outcomes, with a particular focus on at-risk and underserved populations. His research has been published in leading medical and health policy journals, including the *New England Journal of Medicine* and the *Journal of the American Medical Association*, and featured in major media outlets. He has been funded by the National Institute for Occupational Safety and Health, the National Institute on Aging, the California Department of Industrial Relations, and the U.S. Department of Labor. Dr. Seabury is also a faculty research fellow at the National Bureau of Economic Research, a member of the National Academy of Social Insurance, and an associate editor of the *International Review of Law and Economics*. Prior to coming to USC, Dr. Seabury was a senior economist and associate director of the Center for Health and Safety in the Workplace at the RAND Corporation and professor of economics at the Pardee RAND Graduate School.

Teena Shetty, M.D., is a neurologist at the Hospital for Special Surgery (HSS) and is triple board certified in neurology, neuromuscular medicine, and electrodiagnostic medicine. She is the director for the Concussion Program in Neurology at HSS. She specializes in sports neurology, concussions, neuromuscular diseases, myopathies, peripheral neuropathy, intraoperative monitoring, and spine disorders. In addition to directing the concussion program and seeing patients, Dr. Shetty is also an associate professor of neurology at Weill Cornell Medical College. Dr. Shetty is both the neurologist for the New York Mets and unaffiliated Neuro-Trauma Consultant for the New York Giants. In 2011, Dr. Shetty was featured in Crain's New York Business "40 under Forty," an annual listing of 40 successful professionals under the age of 40. She was also featured in the November, 2011 issue of *Marie Claire* magazine presenting eight inspirational professional women in New York City. Dr. Shetty is the principal investigator of multiple grants at the Hospital for Special Surgery, funded by the GE-NFL Head-Health Initiative, Abbott pharmaceuticals, Perseus/Chembio, and TEVA pharmaceuticals. Her research interests include imaging biomarkers in mild TBI, blood biomarkers in mild TBI, barriers to concussion recovery, and postoperative neuropathies following arthroplasty.

April Turner, M.S., C.R.C., is currently the state head injury coordinator for the Alabama Department of Rehabilitation Services. She is also the Traumatic Brain Injury Program director of the Federal Administration on Community Living TBI Partnership Grant, the State TBI Pre-Vocational Care Coordination Program, and Statewide TBI/Spinal Cord Injury Registry Services for the Lead Agency on TBI. Her agency also carries the Alabama Head Injury Task Force and the Alabama Head and Spinal Cord Injury Trust Fund. Recently, she wrote and was awarded a 5-year Administration on Community Living Federal TBI Grant for systems change in the Behavioral Health area for individuals with TBI. Mrs. Turner received her Bachelor of Science Degree in Rehabilitation from Troy University in 1999 and then went on to receive her Master of Science in Rehabilitation Counseling and Vocational Evaluation from Auburn University in 2001. During her master's program, she completed a thesis on, "Characteristics of a Mentally Ill Population Associated with Employability." She began her work for Alabama Department of Rehabilitation Services over 21 years ago. She has also worked as a vocational evaluator, welfare-to-work counselor, transition/general vocational rehabilitation counselor, and as a specialized hybrid traumatic brain injury/vocational rehabilitation counselor.

Rebeccah Wolfkiel, M.P.P., joined the National Association of State Head Injury Administrators (NASHIA) as executive director in January 2018. She brings 15 years of experience in promoting policies that provide resources for individuals with brain injury and their families. In her role as executive director, Rebeccah is committed to representing the interests of state governments and supporting the unique and integral role they play within the service delivery system. Rebeccah also worked with former Pennsylvania Governor Tom Ridge at the Ridge Policy Group for 10 years, where she formerly represented NASHIA as a government affairs advisor. She played an integral role in the successful reauthorization of the Traumatic Brain Injury in 2014, paving the way for the federal TBI program's move to the Administration for Community Living. Prior to her time at the Ridge Policy Group, Rebeccah worked on Capitol Hill for over 6 years where she served as legislative director to Congressman Todd R. Platts, cochair of the Traumatic Brain Injury Taskforce. Managing the congressman's legislative agenda, she learned how to effectively navigate the lawmaking process and develop successful strategies. During her tenure on the Hill, Rebeccah became keenly aware of the importance of bipartisanship and developed strong congressional relationships with Republicans and Democrats alike. She often bridged partisan gaps and facilitated communication between contrasting viewpoints.

David Wright is the founder and chief executive officer of Disruptive Innovations (DI), headquartered in New York City, as well as the host of the

Disruptive Innovators podcast. DI is a digital business and technology consulting firm specializing in helping enterprise organizations with IT strategy and the implementation of transformative solutions that serve to optimize processes, improve workflow, reduce cost, and align technology with the company's business vision. Mr. Wright has worked in the technology world for over 12 years but has been passionate about technology since he was a young boy—building computers and setting up LAN's in his early teens and studying MSCE in his free time by the time he was in high school. He has helped hundreds of clients over the years in nearly every vertical—including health care, retail, financial, and technology. Mr. Wright also has extensive experience in working with private equity firms and their subsequent portfolio companies and is well versed in client asset management, financial modeling and analysis, and relationship management. David has spoken on panels at conferences throughout the United States, and his young organization has received numerous awards acknowledging its achievements. He has a strong understanding of payback models and return on investment in both the public and private sectors.